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TITLE: The development and evaluation of a self-care intervention for informal caregivers of relatives with bipolar disorder.

YEAR: 2016

OpenAIR citation: BOAG, L.S. 2016. The development and evaluation of a self-care intervention for informal caregivers of relatives with bipolar disorder. Robert Gordon University, PhD thesis. Held on OpenAIR [online]. Available from: https://openair.rgu.ac.uk

This work was submitted to- and approved by Robert Gordon University in partial fulfilment of the following degree:
Doctor of Philosophy, Faculty of Health and Social Care, School of Nursing and Midwifery

THE DEVELOPMENT AND EVALUATION OF A SELF-CARE INTERVENTION FOR INFORMAL CAREGIVERS OF RELATIVES WITH BIPOLAR DISORDER.

Thesis submitted for the degree of Doctor of Philosophy at the Robert Gordon University

By

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DECLARATION

I, the undersigned, declare that this thesis entitled **The development and evaluation of a self-care intervention for informal caregivers of relatives with bipolar disorder** has been constructed by myself and has not been accepted in any previous application for a degree. All quotations have been distinguished and their sources specifically acknowledged. Any personal data included in the work have been processed in accordance with the provisions of the Data Protection Act passed in 1998.

Signed:
Lee Steven Boag
December 2015

ACKNOWLEDGEMENTS

My deepest thanks extends to the participants who took part in both the interviews and the intervention pilot. I will always be inspired and in awe of the dedication and resolve of those caring for family members. I hope that the work constructed from your experiences and tested with your efforts can make a difference to yourselves and others in similar situations.

To my supervisor and mentor, Dr Mary Addo, without your knowledge, patience and guidance I would not have been able to accomplish this work. You have been a great source of inspiration and motivation and I am truly grateful for everything you have done for me.

To my secondary supervisors: Professor Susan Klein, for your guidance and accommodation in the Institute when I couldn’t find peace anywhere else, and Dr John Love, for your positivity and feedback.

To the Institute of Health and Wellbeing, my thanks for the PhD studentship award, the support and facilities provided that gave me the opportunity to undertake this piece of work.

A big thank you to Mrs Andrea MacMillan, in particular for her help and her friendship.

To Dr Hector Williams, Senior Statistician I cannot thank you enough for the support and guidance with statistical analysis.

I thank my Mum and my grandparents for their love, support and making me who I am. My mum’s supportive mantra of ‘So long as you try your best.’ has never been repeated so frequently as they have while I was pursuing this work. I thank my friends for their patience and understanding in the last three years where I spent more time talking about research or reading journals than spending time with them.

DEDICATIONS

I dedicate this work in the memory of my much missed Granda Nommie who was taken from us too soon. Although gone, you will never be forgotten and live on in our hearts and memories.

ABSTRACT

Background: Informal caregivers provide unpaid support to a family member, which has been shown to more positively affect their relatives' health outcomes than equivalent paid caregivers. The provision of this support, however, comes at a cost to the carers' health and wellbeing through meeting the demands of the caring role. Efforts have been made to alleviate these consequences through various forms of interventions aimed to enable the carers to meet these demands. The reported success of these interventions is varied in regards to their effectiveness; an argument supported by literature review papers on the subject that questions the methodologies and evaluations of these interventions.

Rationale: There is a need to explore the ways to enhance the health and wellbeing of informal carers by means of a robust design and evaluation.

This thesis reports a study, the aim of which is to provide information about how to reduce the negative effects of the carer role whilst enhancing the positive effects using an intervention developed using lived experience.

Method: The self-care intervention was developed and piloted with those caring for a relative with bipolar disorder. This was achieved in three stages: (i) qualitative interviews with carers to explore and understand the role, (ii) developing the intervention informed by qualitative findings, and finally by (iii) piloting the intervention. Effectiveness of the intervention was determined using health and wellbeing outcomes, the results of which were compared to a control group who did not take part in the intervention.

Results: A positive potential for psychoeducational, cognitive behavioural and mindfulness techniques in enhancing the health and wellbeing of those caring for a relative diagnosed with bipolar disorder was found. From the exploration of lived experience, "Being Bound" was elicited from the data representing the conflict between the detrimental effects of providing care and being unable to take respite or reprieve through guilt and anxiety.

Conclusion: Professionals who work with family members, individually or as part of a family unit, should consider the benefits of targeted information for carers. Provision of information is not enough to engage the carer in the process of understanding their relative's behaviours, but requires a process of interaction and personalisation. In contributing to existing research, the use of hermeneutic phenomenology provided new insight in to the experiences of those providing care. The outcome of the intervention pilot shows positive potential for the use of interventions beyond psychoeducation alone and the use of a self-care approach.

Keywords: *Informal caregivers, bipolar disorder, intervention development, intervention pilot.*

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Abbreviations Used In This Thesis

ATQ – Automatic Thoughts Questionnaire
ATQ-P – Positive Automatic Thoughts Questionnaire
BD – Bipolar Disorder
CBI – Caregiver Burden Inventory
CBT – Cognitive Behavioural Therapy
DRS-15 – Dispositional Resilience Scale -15
EE – Expressed Emotion
FFMQ – Five Facet Mindfulness Questionnaire
MRC – Medical Research Council
NHS – National Health Service
JCS – Jaloweic Coping Scale
SSQ-6 – Social Support Questionnaire -6
UK – United Kingdom
UMDQ – Understanding Mood Disorders Questionnaire
WEMWBS – Warwick Edinburgh Mental Wellbeing Scale
WHO – World Health Organisation
ZBI – Zarit Burden Interview

Chapter One: Background to Research Study and Problem to be Explored

1.1 Introduction

This chapter provides background information of the study and identifies the focus of the investigation. It describes the extent of issues that informal carers are confronted with in their day to day life in caring for relatives in the context of bipolar disorder (BD), the relevance of various policies to that effect, including the researcher's perspective, and the research questions to be addressed. Justification is given for the decision to adopt a mixed method design for the study. To achieve the overall aim the study comprised of three stages that were followed to provide the context.

1.2 Definition, Symptoms and Characteristics of Bipolar Disorder

Bipolar disorder (BD) is a psychiatric disorder, of which the symptoms comprise of depression and mania (Steele, Maruyama and Galynker 2010). The depression involves diminished interest or pleasure, loss of energy, and feelings of worthlessness and guilt. In mania there is distractibility, inflated self-esteem, diminished need for sleep, psychomotor agitation, increased talkativeness, and greater engagement in high-risk activities (MacQueen and Young 2014). Two types of BD have been delineated where Type I describes the experience of both mania and depression that can be separated by euthymic, or 'normal', states. Type II refers to the experience of depressive states predominantly without experiencing a manic episode, however hypomania (increased activity beyond normality but not as enhanced as mania) may be experienced (Jamison 2000; Bennet 2006; Gildengers et al. 2013; Swann et al. 2013).

Persons with BD are at an increased risk of suicide at around fifteen times higher than that of the general neurotypical population (Harris and Barrowclough 1997). However, a more recent study has suggested that this may be an underestimate and suggests that up to a quarter of all completed suicides are associated with BD (Dennehy et al. 2011). Women with BD are reported to be at a higher risk of suicide than men. However, the validity of this claim is questioned as women are more open in the disclosure of suicide attempts, and men more inclined to use 'disguised' methods such as car accidents or risk taking behaviours, which would not be reported as suicides (Jamison 2000).

Impulsivity is also highly associated with BD(Dalley, Everitt and Robbins 2011), whereby a person possesses '*a predisposition toward unplanned reactions to internal or external stimuli'* (Najt et al. 2007 p. 314). This predisposition is prominent in manic mood phases of BD but is observable in euthymic and other mood states (Swann et al. 2003). High levels of impulsivity are related to behaviours that are challenging, aggressive or health endangering relating to risk (Perroud et al. 2011). The effects of such extreme and dynamic symptoms can greatly impact on the lives of those with BD.

The effects of on-going and varying symptomatological consequences can lead to relationship degeneration and job loss (Shastry 2004; Syron and Shelley 2001). Both mania and depression hamper a person's abilities to critically think, concentrate, gage risk and deficit the verbal working memory and processing speed, which can lead to strains in routine aspects of life (Gildengers et al. 2013), such as communication, self-organisation and overall functioning (Judd et al. 2005). The most prominent effects of BD tend to be depressive symptoms which lead to a relatively high rate of misdiagnosis which through misappropriated treatment, can induce manic states or even increase mood cycling (Perlis 2005).

Symptoms exist in relation to both the depressive and manic mood states of BD resulting in dangerous and self-damaging behaviours (Baldassano 2004; Bennett 2006). Whilst experiencing manic mood states spontaneity and short sightedness of actions can lead to financial and occupational difficulties and relationship degradation. Conversely, depressed mood states can lead to increased risk of substance misuse (Baldassano 2004; Maskill et al. 2010). High levels of psychiatric co-morbidity are also associated with 1 in 2 persons with BD experiencing at least one anxiety disorder (Perlis 2005; Peroud et al. 2011).

1.3 Prevalence, Development and Course of Bipolar Disorder

Between 1 and 3% of the population are thought to experience BD at one point in their lives (Jamison 2000; Chakrabarti and Gill 2002), with type I as the most prominent (Goossens et al. 2008). It has been recognised by the World Health Organisation (WHO: 2012) as the sixth leading worldwide cause of disability, however lower rates of prevalence have been recognised in Asian and Hispanic populations(Burnett-Zeigler, Bohnert and Ilgen 2013). It affects both sexes equally but women have reported fewer manic episodes and faster cycling between mood states (Burnett-Zeigler, Bohnert and Ilgen 2013). The first episode normally occurs between the ages of eighteen and thirty but can affect all age groups and these episodes can last days, weeks or even years (Ketter 2010).

1.4 Aetiology

The aetiology and pathophysiology of BD are not well understood due to the complexity of the brain function for the condition (Shastry 2005). However, neuroimaging and biochemical analyses infer structural differences in brain regions such as the amygdala, basal ganglia and areas of the prefrontal cortex (Kempton et al. 2011) and alterations in the serotonergic and dopaminergic neurotransmitter systems (Fountoulakis et al. 2012). These differences are thought to contribute to the depressive symptoms of the condition and such brain changes could affect brain circuitry.

Studies regarding families, twins and adoption have indicated that BD is a heritable condition through identifying increased risk in first degree relatives (Meda et al. 2012) and higher concordance rates is monozygotic twins (O'Reilly 2013). These increased risks reflect a genetic component to the causes of BD but no specific gene has been identified as a cause resulting in the belief of a multigene interaction (Shastry 2005).

In regards to environmental factors, stressors can trigger episodes in those who are genetically predisposed (Kempton 2011). Alongside life events, social support has been found to positively and negatively affect the course of the illness depending on the approach taken by the supporting person (Alloy et al. 2005), including familial attachment and environment (Cooke et al. 1999).

1.5 Background to the research study and extent of the problem

A hidden population of approximately five to six million effective (caregivers are estimated within the United Kingdom (UK) Hunt 2000), providing care for relatives and spouses with ill health (Deekan et al. 2003). Known as informal caregivers, they face a multitude of psychosocial detriments in response to their role (Steele, Maruyama and Glaynker 2010). Those caring for a relative with bipolar disorder (BD) are highlighted to be at increased risk compared to other caregivers due to the nature of the illness (Chakrabarti and Gill 2002). Research in to the experiences of those caring for relatives with BD specifically, is relatively limited by comparison to other caregiver roles (Reinares et al 2006; van der Voort, Goossens and van der Bijl 2009).

Critical reviews regarding caregiver intervention research (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002) have highlighted mixed success in the alleviation of caregiving role consequences and have emphasised the benefits of pilot studies whereby the processes of recruitment, retention and acceptability can be further understood. It has also been indicated that the very perspectives of how and what interventions target can greatly affect the effectiveness of intervention assistance (Nolan, Grant and Ellis, 1990; Ogilvie, Morant and Goodwin, 2005; Perlick et al. 2007; Justo, Soares and Calil 2009; Steele, Maruyama and Glaynker 2010).

These papers question the reliance upon health related outcomes without consideration of wellbeing, the use of singular component interventions that may not fully accomplish what complex interventions could do, and reliance upon unjustified measurement tools that can lead to false positive or even false negative results. This intervention project reported in this thesis has been shaped by these recommendations for future caregiver intervention research to produce a multi-component self-care intervention that was piloted, to further understand the potential positive indications of intervention assistance with those who care for a relative diagnosed with BD.

1.6 Researcher's Perspective

In accordance with the philosophical assumptions underpinning Gadamer's hermeneutics and phenomenology (1976 and 1989), which forms the qualitative part of the mixed methods design, the researcher has to declare their presuppositions and fore understanding which they interpreted and understood the lived experiences of those they interacted with. The researcher was a white, agnostic, native British male and 23 years old at the beginning of the research study. He has an academic background in psychology and counselling with research experiences with older adults and children in relation to motor skills and with patients in relation to side effects of anti-acne medication. He has occupational experience as a mental health support worker in rehabilitation studies with persons with varying mental health conditions, working with families as a community caregiver and support group facilitator for those diagnosed with BD and other mental health conditions.

Through this, he has developed an understanding of recovery in mental health and witnessed the day to day experiences of those who care for a relative diagnosed with a mental health disorder at home. As the role of community care worker related more so to the relative who was mentally unwell, no formal training was given regarding working with the family members. Despite this, continual contact, albeit brief in some cases, allowed the researcher to understand that the role was challenging, and a very unique experience dependent upon the particular illness presented by their relative.

Having facilitated a support group for those with bipolar disorder, the researcher has experience of the range of behaviours and personal experiences of those living with the bipolar illness but not their families or care givers. Previously having been in a counselling role, the researcher brings the skillset of listening to and deeply understanding a speaker to aid the hermeneutic process, by both eliciting more lived experiences through verbal interaction and demonstrating understanding of others lived experiences through empathy.

He holds high regards for theories pertaining to wellness and improved psychological health beyond the absence of illness (Richmond 1979). As he has worked with others for most of his life, he regards human experience to be implicitly multifaceted and unique; and human consciousness as so complex that it may only be truly expressed by a shared understanding of personal expression, through the selection of words to portray experience.

With limited experience with qualitative methods prior to the study at hand, the engagement with and selection of phenomenology was shaped through personal views of language, the benefit in true understanding of another person, the sharing of personal experience and an appreciation of the spoken word. From this background, the researcher brings to this research his pre-conceptions and understandings on the phenomenon being examined in this thesis.

1.7 Structure of the research study design stages

This thesis addresses the issue of the impaired health and wellbeing of those providing informal care for a relative with BD. The study was carried out in three stages with each stage informing the subsequent stage. They can be reductively be understood as : (i) undertaking a qualitative exploration to gain an understanding of lived experience of an intercept population, (ii) the development of a multicomponent intervention informed by the results from Stage 1 qualitative exploration of lived experience, and (iii) the longitudinal pilot of the developed intervention.

Stage One

This stage of the research study explored the lived experiences of those who provide care for a relative with BD. The information was attained using a phenomenological approach to help provide data that is information rich, pertaining to the experiences of the target population, and used in conjunction with caregiver intervention research literature, to design a robust multi-component intervention.

Stage Two
Here, the development of a robust multi-component intervention was undertaken which was informed by the outcome results of Stage One. An evaluation of the intervention was developed, with consideration of feasibility trials, and also limitations and suggestions from previous caregiver intervention research literature.

Stage Three
In Stage 3 a longitudinal pilot evaluation of the intervention developed and evaluated in accordance with Stage Two was undertaken. Participants engaging with the intervention for four months were assessed using health and wellbeing outcome measures at pre- and post-intervention phase. Involvement and interaction with each component was evaluated using direct and accurate measurements to reflect engagement. The results provide findings that will illuminate how to effectively negate the impacts of the informal caregiving role and provide feasibility data for larger scale interventions.

1.8 Structure of the thesis

The thesis is divided into seven chapters. Chapter 1 gives background information to the research study, the extent of the problem to be explored, definition of terms, issues relating to bipolar disorder, the researcher's perspective, the structure of the three stages of the whole study, and finally the structure of how the thesis is presented.

Chapter 2 presents an overview of literature search strategy for previous research studies with informal care givers, gaps identified in existing literature evidence, and the relevance for developing a multicomponent self-care intervention informed by lived experiences, rationale for piloting, in order to set the context of the research study.

Chapter 3 gives an overview of the research design and methods, the rationale for adopting a mixed method research methodology and design, including the scope and flow of the connection between the three different stages of the study, and related ethical and methodological legitimation issues.

Chapter 4 explains the development of a multicomponent self-care intervention, how the qualitative findings from Stage 1 combined with relevant intervention research literature evidence informed the intervention development in Stage 2, the rationale for feasibility evaluation of the developed intervention.

Chapter 5 presents the combined results of Stage 1 (qualitative) and Stage 3 (quantitative). Stage 1 results show the themes and their supporting verbatim direct quotes to illustrate and give a description of the common features of the informal carers' experience. The quantitative statistical analysis is presented in tables illustrating the acceptability, meaningfulness and effectiveness of the developed intervention.

Chapter 6 provides a discussion drawing on the synthesis of the overall qualitative and quantitative results and linking this to existing and relevant literature.

Chapter 7 provides information on the original contribution made to knowledge, reflection on the study, appraisal of the limitations and strengths of the study, overall insights provided from the study, relevant implications for policy, practice and future research, conclusion and recommendations of the study.

Finally, each participant's historical background and interpretation of narratives for Stage 1 of the study are located in appendix five.

1.9 Chapter summary

This chapter has set out the context of the study and how the thesis is structured.

Chapter Two: Literature Review

2.1 Introduction

The purpose of this literature review was to examine previous studies on the consequences faced by those who provide care for a relative with bipolar disorder (BD) in order to formulate an argument for the justification and relevance of undertaking this research. Further in-depth discussion of the literature will appear in the discussion Chapter 6 of the thesis, where findings from the phenomenological study in Stage 1 and the intervention development in Stage 2 of the research are linked to a more specific literature.

2.2 Literature Search Strategy

Searches to identify relevant articles for this review were conducted using a combination of subject headings such as 'informal care(r)(ing)', 'bipolar disorder', 'care(r)(giver) burden', 'experiences', 'relatives', 'home care(r)', 'coping' and 'intervention(s)'. Databases searched were ScienceDirect, Medline, OVID full text journals and PsychINFO. No time frame was set for the searches. This search strategy provided 36 relevant journal articles and 2 books. Further reading was supplemented with hand searching of psychology, social work, nursing and psychiatry journals and relevant books that related to aspects such as caregiving in general, caregiving for those with conditions other than BD, intervention development, feasibility trials, assessment tools and the development of informal caregiving.

In regards to the texts and articles used pertaining to hermeneutics and phenomenology, the sources cited reflect the original contributions of the founding philosophers and also sources that the researcher of this study felt supported these arguments with the most clarity. These sources are not selected for their recency, but rather for their content as the underpinnings of the approaches require clarity rather than modernity (Mays and Pope 2000).

2.3 Research on Informal Caregivers

2.3.1 The emergence of the 'Informal Carer'

The deinstitutionalisation movement resulted in a shift of treatment and patient care towards out-patient hospitals and supported living at home from the 1950s onwards (Dore and Romans 2001), and was notably aided by the Mental Health Act 1960 (Grad and Sainsbury 1966). This shift has increased the numbers of those providing care for a person with a mental illness. These people are referred to as informal carers and are defined by Hunt (2003 pp.28) as "*an unpaid person who helps a person with physical care or coping with a disease*."

A high proportion of the population are classified as informal carers with approximately 5 and a half to 6 million people providing regular care for a family member or friend having been identified in 2001, and this number has remained relatively constant to the present day (O'Reilly et al. 2008; Legg et al. 2012). The peak age of informal caregivers is between 45 and 59 years old and is a role more often fulfilled by females until older adulthood, at around seventy, where men are more likely to provide care (Dahlberg, Demack and Bambra 2007; Legg et al. 2012).

Patients with BD have reported that they recognise the importance that their family members who provide care and support are to them and their continued health (Russell and Browne 2005; Michalak, Yatham and Kolesar 2006). This patient perception is reinforced by research in to the informal caregiving role, which has revealed that the care delivered by an informal carer can greatly reduce levels of relapse, improve physical and mental health, and meet more of the care recipients' needs than paid assistants or volunteers (Lincoln 2000; Deekan et al*.* 2003), which is thought to be in part due to love and filial bonds (Rowe 2011). However, providing care for a mentally unwell person can dramatically impact on the lives of those in that care giving role (Dore and Romans, 2001; Ogilvie, Morant and Goodwin, 2005; Eisner and Johnson, 2008; Rane et al*.* 2012).

2.3.2 Informal Caregiver Burden

The role of an informal carer comes with many consequences and research in this area has led to the development of the umbrella term 'carer burden' to encompass the observable and perceivable negative and detrimental effects experienced by informal carers, such as: the incidence of adverse effects or difficulties affecting the lives of those caring for a person with an illness (Chou 2000; Hunt 2003; Goossens et al. 2008).

The term 'family burden' was introduced in 1966 by Grad and Sainsbury in a paper evaluating how the mentally ill were cared for in the community and the impacts that living at home had on their families. They described burden as any cost to the family of the care receiver. However, it was recognised by Hoenig and Hamilton (1966) that separable components of burden were needed to differentiate between situational and emotional reactions; the objective and the subjective. Montgomery, Gonyea and Hooyman (1985) further defined the components of burden as objective: the level of disruption or change in the caregiver's life, and the subjective: the caregiver's attitudes and emotions, with both of these relating to the caregiving experience.

Presently, carer burden is defined as objective or subjective depending on which area of the caregiver's life they affect (Shah et al. 2010). Examples of objective burden include practical problems; financial difficulties, negative impacts on their health, interruption of family relationships and constraints in both social inclusion and occupational matters. Subjective burden refers to the psychological reactions that carers experience, for example, feelings of loss and frustration for the changed relationship between themselves and the care recipient, isolation and loneliness from radical change in routine with less spare time, and the stress of coping with the role and challenging behaviours (Maskill et al. 2010).

Whether objective or subjective, such burdens have consequences on the health and wellbeing of those who care for a person with a mental health disorder (Nolan, Grant and Ellis, 1990; Ogilvie, Morant and Goodwin, 2005; Perlick et al. 2007; Steele, Maruyama and Glaynker 2010) and also impact on the quality of care they can provide with increased rates of relapse and unmet needs coupled with decreased activity for the care receiver when perceived burden is high (Chakrabarti and Gill 2002; Deekan et al*.* 2003). Factors that were found to increase burden included the severity of the care receivers' symptoms, length of illness and frequency of hospitalisations (Dyck et al*.* 1999; Hudson et al. 2012).

2.3.3 Assessing Carer Burden

Efforts to develop tools to measure and assess the severity of carer burden led to the development of The Zarit Burden Interview (ZBI: Zarit, Reever and Bach-Peterson 1980) This development was a shift from the usual paradigm of interview schedules to a self-report questionnaire comprising of 29 items, in which the informal caregiver responded to questions regarding health, well-being, social inclusion, financial circumstances and the relationship between themselves and the care receiver.

Whilst the ZBI was very well received and has, at present, been refined to a 4-item screening tool (Bédard et al. 2001) which is still widely utilised in the healthcare system (Deekan et al. 2003), the unidimensional considerations of the multifaceted experience of informal caregiving limits the exploration, and hence understanding of the specific areas of need requires to develop a targeted intervention to alleviate the consequences of the informal caregiving role (Vitaliano, Young and Russo 1991). The Caregiver Burden Inventory (CBI: Novak and Guest 1989) addressed the unidimensional issue of caregiver burden by deriving items from caregiver experiences and previous carer burden literature. In total, twenty four items were constructed and loaded on five factors: time-dependence burden, developmental burden, physical burden, social burden and emotional burden.

The CBI considered both objective and subjective responses with items responding to task-specific and affective responses to burden. Despite the multidimensional design of the CBI, the five factors of burden were not thought to suitably reflect the efforts of identifying specific areas of need (Vitaliano, Young and Russo 1991).

In recognising that summative global scores of burden were potentially masking dimension-specific patterns of the consequences of informal caregiving (George and Gwyther 1986; Kosberg, Cairl and Keller 1990) the Cost of Care Index (CCI) (Kosberg and Cairl 1986) was developed. The CCI included subscales which finally allowed clinicians and researchers to explore and analyse the various components contributing to burden (Deekan et al. 2003), thereby addressing the limitations of summary scores which would not have informed clinical appraisal to specific areas of need.

Continuing with this manner of heuristic approach, Vitaliano et al*.* (1990) derived a multivariate model to elucidate burden and determine the factors that could predict it. The model was created in regards to those providing care for older adults with Alzheimer's disease but well reflects the movement to multivariate analysis and measurement within the field of informal care at that time. The model illustrated three separable origins of subjective burden and distress: vulnerabilities, stressors and resources (Dyck, Short and Vitaliano, 1999) and could be expressed as: "Burden = (Exposure to Stress X Vulnerability) / (Psychological and Social Resources)." (Dyck, Short and Vitaliano, 1999, pp. 412), i.e. that burden was comprised of stress exposure to a magnitude of how vulnerable the caregiver was which would be proportionally offset by psychosocial resources.

Montgomery, Gonyea and Hooyman (1985) defended the use of global scores in the assessment of burden if the assumption was made, that an accumulation of stresses contribute to burden and that burden leads to breakdown in the family care system. However, without knowing the specific areas of need a targeted intervention cannot be constructed to alleviate the negative consequences of the role (Kosberg, Cairl and Keller 1990). An attempt was made to mediate this argument by suggesting that the choice of domain-specific or global measures of burden should be made in regards to the nature of the research (Zarit 1986), with the use of domain-specific measures only when the nature and severity of the consequences of burden are of interest (Kosberg, Cairl and Keller 1990). Despite this, as the number of papers focusing on caregiver burden rose, it became clear that the term 'burden' had not yet been properly conceptualised (Poulshock and Deimling 1984; Kosberg, Cairl and Keller 1990; Deekan et al. 2003), and it was recognised by Poulshock and Deimling (1984 pg. 230) that "[a]ttempts to derive specific measures from a concept so broadly defined result in a lack of precision" and went on to describe the attempts at splitting burden into objective and subjective measures also inadequately portrayed the subsumed experiences and consequences.

This observation of the term burden resulted in two choices for the future of burden research: conceptualise burden to allow for cross-sectional comparisons with a standardised and consistent concept or to approach assessment of the caregiving experience in a manner that considers the consequences of informal caregiving without the reliance of an umbrella term. Following this choice, efforts were made to conceptualise carer burden through reviews and conceptual analysis (Houlihan 1987; Chenier 1997; Chou 2000) but the issue of the unidimensional approach to the comprehension of complex experiences encouraged researchers to develop novel ways of understanding the informal caregiving experience.

Tringali (1986) developed the Family Needs Assessment (FNA) which explored caregiver needs in relation to cognitive, emotional and physical aspects. The FNA inspired a shift in assessment of the caregiving experience towards identifying the areas of caregiver need, and identifying specific costs of caring which further set the basis for research that would identify the variables that led to burden for informal caregivers rather than relying upon the summative burden scores to identify need (Chenier 1997).

2.3.4 Assessment of Caregiver Needs

As with the term 'burden', a lack of conceptualisation for 'need' became the cornerstone of most arguments against needs assessment research. Lightfoot (1995) recognised that the origin of the definition of 'need' was a multitude of overlapping perspectives from a variety of disciplines and that the word itself was so complex that reaching a consensual agreement of the term would be unlikely. Lightfoot carries on to question the notion that needs can be organised hierarchically; "that is, the existence of different levels of need" (pg. 106). The premise of needs arranged in order of predominance stems from Maslow's (1943) 'A Theory of Human Motivation' in which Maslow states that *"[h]uman needs arrange themselves in hierarchies of prepotency. That is to say, the appearance of one need usually rests on the prior satisfaction of another, more pre-potent need. Man is a perpetually wanting animal*." (pp. 370).

This vantage taken by Maslow insinuates that, need is something to be fulfilled in a specific order and that each time a need is met, it is superseded by a new need initiated by the fulfilment of its antecedent. Although Maslow goes on to describe the process of "self-actualisatization" which is associated with a subjective and introspective aspect of self-fulfilment (Maslow 1943; McLeod 2003; Mearns and Thorne 2007), the hierarchical view of needs lends itself back to objective measurement and would limit the scope of assessment leading to possible failure to appreciate the many variables within the caregiving experience (George and Gwyther 1986; Lightfoot 1995; Shah, Wadoo and Latoo 2010).

Cowley et al. (1996) recognised that the "*idea of a concept of 'need' itself is personal, subjective, variable, and constantly changing*" (pp. 57) and encapsulates the ethos of a more in-depth individual needs assessment which was emphasised by the National Health Service (NHS) and Community Care Act (1990). The act stated that individual needs assessments should be carried out to ensure that adequate and suitable provisions of care were put in place for those in need of long term care, and despite the research done in the areas of carer burden and needs, those providing care for a relative were still commonly viewed as a resource within these policies and references of needs assessments focused on whether the care recipient's needs could be attended to and which services they should be directed to (Pickard 2001).

2.3.5 The Importance of Understanding the Role of the Informal Caregiver

Although acts such as the NHS and Community Care Act (1990) had limited consideration for the informal caregiver, research of the time was evolving to consider various other measurements of the impacts of informal caregiving and how these could prove advantageous to intervention development. An example of the existing considerations of the informal carer is a literature review undertaken by Goodman (1986) which sought to describe who informal carers were and what they did in light of limited knowledge in this area. Goodman highlighted several limitations of research that aimed to assist informal carers: subjective professional judgement, underestimation of the problems experienced and narrow outlooks of assessment.

Subjective professional judgement referred to the lack of consistency between health professionals in their decisions of treatment through lack of conceptualised concepts and a heavy reliance on subjective opinions. This led to a concern that without a reliable and comprehensive agreement of concepts relating to health and wellbeing, that treatments and opinions would not be consistent, and outcomes of research would be limited by indistinct variables. Underestimation of the problems experienced was exemplified through possible social desirability of responses of informal carers when questioned regarding coping which Goodman (1986) suggested could arise from being "*anxious to be seen as coping and uncomplaining*" (pp. 706). Goodman expressed concern that a desire to be seen as managing could be masking the levels of perceived strains and consequences, thereby only "*describing the tip of the iceberg*" (pp. 712). The narrow outlooks of assessment could also be concealing the true lived experiences, demonstrated through previous studies in this area failing to examine wider support networks and length of time providing care.

In light of these concerns it was clear that further consideration of the role should be undertaken to better allow a comprehensive understanding of the informal caregiving experience. Smith et *al*. (1991) produced a paper in which the problems of concern for informal caregivers through counselling were identified. The authors recognised that "*practitioners may focus on intervention techniques that are inappropriate for this target group*" (pp.16) if they do not identify the aims of the informal caregiver, and took this further by suggesting that the fulfilment of these goals should comprise the evaluation of support rather than global indices and omnibus psychological measurements.

Individual considerations such as these display the changing views of intervention treatments and how specific groups and individuals should be targeted for interventions to provide optimal benefit for those who use them. Wright and Leahey (1994) coined the term monocular focusing to critique the previous narrow sighted emphasis of previous interventions on either the social dynamic of the family or the interventions themselves. The authors suggest a binocular focusing that encompasses both of these aspects to provide a 'fit' between individual need and the intervention offered by the healthcare professionals, so that goals could be set and targeted through collaboration of both the individual receiving treatment and the healthcare professional. This stance echoes the earlier work of Nolan, Grant and Ellis (1990) who appreciated that subjective perceptions are understood to be the driving forces behind stressors rather than objective events and circumstances alone.

The progressively changing stance of informal carers as individuals and requiring specifically targeted treatment eased the way for changes in legislation regarding those who care for a patient. The Mental Health Act 1983 part II delineated the function of relatives of patients, or those appointed as such, in so far as their purpose towards patients and their care. However, the Carers (Recognition and Services) Act 1995 introduced the right of assessment for those providing care for a relative in England and Wales and then Community Care and Health (Scotland) Act 2002 to incorporate those in Scotland. The assessment would be conducted by local authority and focused to ensure that relatives could provide, and carry on providing, care.

Standard six of the Department of Health National Services Mental Health Framework (1999) further extrapolated this carer-centred approach and emphasised that, informal carers should have assessment made of their caring, physical and mental health needs and have their own written care plan. The emphasis of assessment set to amend the 'patchy' adherence of the Carers (1995) Act as provision of assessment and implementation of support were inconsistent. Standard six continues by stressing the importance of paying attention to the needs of carers so that assistance can be targeted, and is appropriate. However, in a five year follow up it was highlighted that little progress had been made regarding the standards of services for informal carers, despite emphasising their importance in relation to patient recovery (Department of Health 2004).

The intentions of these initiatives were to improve the outcomes for informal carers through being informed, assisted and treated with respect to person-centred principles (Nicholas 2003). Regarding informal carers at an individual level, highlighted the need to move away from earlier measures of the consequences of the role that only focused on relieving stress or perceived strain and move towards a more holistic approach, i.e. one that considered the full experience of the person in their role (Murray et al. 1997; Nolan et al. 2001; Nicholas 2003; Ogilvie, Morant and Goodwin 2005). With a scope of wider consideration, indirect effects such as limited time, energy and money available for other aspects of the carer's life that could impact on their social life, work and other relationships were taken in to consideration (Oyebode 2003). In recognising these individual differences, caregiver research was refined and it highlighted that each unique experience was not dependant solely upon objective tasks, but rather than on the perceived role and what it entailed for each person regarding aspects of the role, including staying positive, providing motivation and emotional commitment (Nolan et al., 1990; Nolan et al., 1996).

This shift in focus inspired the appreciation of positive and protective factors associated with informal care provision, such as pleasure from interpersonal dynamics, and appreciation of the outcomes of the role, e.g. keeping their relative out of hospital or diminishing symptoms (Grant et al. 1998).

2.3.6 Informal caregivers of relatives diagnosed with bipolar disorder

Previous research into interventions for informal carers has heavily been aimed at a general population of informal carers, or those caring for the elderly (Visser-Meily et al. 2005) and in relation to those caring for patients with mental health conditions, schizophrenia is consistently the preferred prototype (Goossens et al*.* 2008). However, little focus exists to date on those providing care for persons with BD and studies that do tend to only highlight areas of need, rather than focusing on how to address them. Considering that BD is the sixth highest cause of disability worldwide (Steele, Maruyama and Glaynker 2010), and its chronic yet variable course, there is reason to believe that the experiences of informal carers of persons with BD may be different, from those of other patients with mental health disorders (Chakrabarti and Gill 2002).

The aforementioned variability of mood and behaviour coupled with the chronic nature of BD contributes to a higher degree of carer burden, due to coping with mixed states of mania and depression, with many informal carers stating that even when things are relatively settled with their care recipient, they anticipate future change which contributes to a degree of stress and anxiety (Reinares et al*.* 2006; Shah et al. 2010). Gallagher and Mechanic (1996) compared those providing informal care for a mental health condition to those who were not carers and found that, the informal carers, self-reported poorer physical health, activity limitation and healthcare service utilisation.

Ogilvie, Morant and Goodwin (2005) also recognised that carer burden was high in informal carers of BD but critiqued previous studies for small sample sizes, the use of non-validated self-report questionnaires, and the inclusion of confounding variables. Such factors would limit the applicability of findings regarding the lives and experiences of those providing care for a relative with BD. Nonetheless,   several studies have used measures that can be considered robust against the critiques outlined by Ogilvie, Morant and Goodwin (2005).

Perlick et al*.* (1999) reported the baseline findings of a longitudinal investigation of carer burden and patient outcome in BD. 93% of 266 caregivers reported moderate or greater distress in at least one domain of burden in the global burden scale. It was found that in addition to the effects of their care recipient’s clinical state, that 18-28% of variance in burden could be explained by the informal caregivers’ beliefs about the illness. These beliefs included awareness of the illness and their perceptions of family control and the care recipient. Showing that personal views and beliefs could contribute so highly to burden, Perlick et al. displayed the importance of attending to these subjective perceptions if interventions were to be targeted and effective.

Further exploration of what matters to informal carers was conducted by Reinares et al. (2006) where 86 informal caregivers or persons with BD completed the Subjective Burden Scale. Results showed that the caregivers experienced a moderate level of subjective burden, with the highest levels of distress emanating from the behaviours of their care recipient, in particular: hyperactivity, irritability, withdrawal and sadness. Proving causation between experiencing challenging behaviours would have allowed for informed development of interventions aimed at assisting in coping with these.

However, Reinares et al. did not include a control group for comparison and the informal carers who participated had to be caring for someone in a euthymic stage which is not representative of those caring for persons with more severe forms of BD. By omitting those who may be experiencing more dramatic effects of illness by those they care for, and having no comparative group, the findings of the paper are limited and can only indicate towards potential focus for future intervention development.

Robust findings regarding the source of consequences for informal carers were displayed by Perlick et al. (2007), where 89% of those caring for a relative with BD reported that they experienced burden in relation to dealing with challenging behaviours. In showing that such a high percentage of caregivers experienced negative consequences with problem behaviour, the work of Perlick et al. (2007) informs the inclusion of training caregivers to deal with challenging behaviours to maximise the efficacy of an intervention.

As the focus on the experiences of caregivers for a person with BD grew, the interest in gaining full insight into the lived experiences of the role led researchers to explore the possible benefits of the role. By attending to the positive as well as the negative, researchers hoped to fully engage in the experiences of the caregivers, and be able to provide more targeted and focused assistance (Hunt 2003). Brouwer et al. (1999) explored informal carers in regards to process utility, in which value "*is not only derived from outcomes, but also from the way this outcome is accomplished.*" (pp. 85). Of 950 informal carers, 48.2% were reported to derive process utility and, on average, when provided with a hypothetical scenario in which someone would take over their role of caring for their care recipient, they reported lower levels of happiness.

Considering the difficulties that can arise in the provision of informal care, and finding that the majority of carers would not relinquish their role, indicates a strong sense of duty. The proportion of those who provide informal care but do not identify themselves as 'caregivers' suggests, a deep and genuine commitment to the person that they care for, and a determination to provide care for them (Lawn and McMahon 2014).

The exploration of the possible positive conceptualisations of caregiving can lend credit to this sense of duty. In a literature review by Hunt (2003), five distinct areas of positive aspects of the role are delineated: caregiver esteem, uplifts of caregiving, caregiver satisfaction, finding or making meaning through caregiving and gain in the caregiving experience. Nolan et al. (2001) provided the six senses in the context of caring relationships, making use of a relationship-centred rather than person-centred approach to understanding the caregiving role. In doing so, Nolan et al. took appreciation of the wider influences on informal carers and delineated the importance of how one is valued, viewed, supported, and satisfied by one's efforts in the caregiving relationship. In attending to such positive aspects, the caregiving role can be considered as a whole and interventions can work to minimise the difficulties whilst maintaining and highlighting the potential benefits to maximise the impact of intervention assistance to the wellbeing of caregivers and improve the training of healthcare professionals who work with them (Hunt 2003; Ogilvie, Morant and Goodwin 2005; Reinares et al. 2006).

Continuing with a relationship-centred proposal, a grounded theory approach by van der Voort, Goossens and van der Bijl (2009) examined the burden of fifteen informal caregivers of spouses with BD and found high levels of burden and isolation, feeling 'alone together' with their partner. The caregivers felt that they were isolated, unsupported, and that their efforts were not recognised. When these experiences are referred to by Nolan et al.'s (2001) six senses, the perceived positive aspects of the role would be reduced. This would impact upon the caregivers' wellbeing and potentially their health (Legg et al. 2012; Zendjidjian et al. 2012). Also, regarding coping styles, the participants were found to appraise situations, trying to strike equilibrium between the demands of the role, attending to their own needs and found higher levels of self-effacement when burden was high. This association with high burden and low levels of self-care could reflect the downward spiral effect of ineffective coping styles, and emphasise the need to encourage healthier coping styles to mitigate negative consequences.

Zendjidjian et al. (2012) recognised the importance of exploring the quality of life (QoL: a standard of health and happiness) of informal caregivers for BD, as it encompasses several dimensions and could enrich the knowledge base of the experiences they face. QoL was found to be impaired predominantly in psychological well-being and social inclusion domains. Now backed with QoL research, the experiences of informal caregivers have been explored to a point where it is possible to utilise this information to inform the development of intervention care.

2.4 Research rationale: The Need for a Multicomponent Self-Care Intervention and Pilot Developed Using Lived Experience

In 1993, Knight, Lutzky and Macofsky-Urban questioned how effective interventions had been in caregiver research. They recognised the limitations of previous interventions as: failure to measure multiple outcomes, lack of attention to differences between types of intervention and confounding variables. Firstly, the use of single measure outcomes would have diminished the ability to observe the effects of support as some measures are more sensitive and the use of general burden scales may have overlooked potential benefits by generalising improvements. Secondly, using the same type of intervention throughout may also mask potential benefits of certain forms of intervention for some people. For example, some people may respond better to specific types of delivery or content (Sörensen, Pinquart and Duberstein 2002). Thirdly, confounding variables such as relationship to the care recipient, adherence to intervention instruction, and level of professional support all have the potential to directly influence well-being and burden measurements, despite the content of interventions.

Ogilvie, Morant and Goodwin (2005) summarise this necessity for precise, robust and targeted interventions: *"There is a need for a formal instrument with practical utility, informed by the experiences of existing caregivers and with defined psychometric properties, specifically designed to capture the nature and extent of burden in caregivers of bipolar disorder."* (pp. 30). To meet the predefined criteria of such an intervention, the design would have to be informed by the lived experiences of informal caregivers, be developed in a way to incorporate a multicomponent design to explore the effects of content and delivery, control for confounding variables, and make use of standardised and validated measurement outcomes to explore the components of the experience, rather than using global scoring measurements (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002; Ogilvie, Morant and Goodwin 2005; Reinares et al. 2006; Goossens et al. 2008).

Interventions for those caring for a person with BD have been primarily psychoeducational in their focus and meet some of the above criteria discussed from caregiver intervention review research. Jonnson et al. (2011) showed changes in coping following intervention. The study did not include a measurement of knowledge or understanding, however, limiting the inference of causation. The caregivers' situations were also assessed using an assessment tool developed for older adults although the mean age of participant in the study was just over 47. The typology of care would be considered different between older adults and those with BD (Rusner et al. 2012).

Bland and Harrison (2000) measured change in knowledge following family psychoeducational sessions and found changes in caregiving behaviour. The study redesigned due to low recruitment rates and forewent a control group to allow all 11 participants to take part in the study. The intervention program showed decreased distress and better coping following psychoeducation and exemplifies the necessity of a psychoeducational component in a larger multicomponent intervention.

Bernhard et al. (2006) developed an intervention with both psychoeducation and cognitive behavioural therapies, recognising that a complex intervention could be potentially more effective (Ogiilvie, Morant and Goodwin 2005). No significant change in burden was observed but with no control group or direct measurement of cognitive behaviour, the benefits of multicomponent interventions for those caring for a relative with BD are still unclear.

Madigan et al. (2012) investigated the effects of multifamily psychoeducation and psychotherapy on family members caring for a relative with BD compared to a smaller sample receiving treatment as normal. Improvements were found in both groups in relation to knowledge, quality of life and overall distress. The study used a two year longitudinal design and shows great potential benefit for caregiver interventions.

2.4.1 Rationale for Utilising Lived Experience

Lived experience can be understood as the awareness of life and the appreciation that events and thoughts shape our existence (Casterlé et al. 2011). Development of an intervention based on lived experience would allow for the intervention to be targeted specifically to the role of caring for a person with BD (Ogilvie, Morant and Goodwin 2005), which is thought to arise through the dynamic and chronic changes to their relative’s behaviours, and can occur out with the symptomatic mood states of depression and mania (Chakrabarti and Gill 2002; Justo, Soares and Calil 2009). When a there is limited understanding of a particular phenomenon, lived experience can be used to understand what is not intuitively available, and in doing that help broaden the knowledge of that topic (Cohen and Omery 1994). Furthermore, lived experience may provide greater opportunity to create effective intervention assistance, which is targeted through improved insight that encapsulates a deeper and richer appreciation of human experience (Giles 2012; Irwin 2012).

Rusner et al. (2012) recognised the necessity to understand lived experience also and used a form of descriptive phenomenology to understand the experiences of those caring for a relative with BD. The process resulted in three main themes that encompass substantial and diverse detail. The process utility for intervention development of broad themes is relatively low as the information required on lived experiences to develop a targeted intervention would be concise and defined (Montgomery 1996; Lancaster, Dodd and Williamson 2004).

Such experience delineation would infer the need for a more in depth and less limiting form of exploration of experiences (Lopez and Willis 2004). Phenomenological approaches without bracketing experience would be advantageous for providing information to develop a targeted, and therefore more effective, intervention (Ogilvie, Morant and Goodwin 2005; Casterlé et al. 2011).

2.4.2 Rationale for Piloting Developed Intervention and Feasibility

It is not only from an existential stance that interventions can be improved but also through piloting (Hudson et al. 2012). Pilot studies act as small scale explorations to allow for the justification and informed planning of larger comprehensive investigations. (Innes 2012) Also known as feasibility studies, a pilot can inform not just the prospective effectiveness of an intervention but also the design, implementation and evaluation of said intervention (Lancaster, Dodd and Williamson 2004). Full scale interventions can greatly benefit from the information generated by pilot studies with reference to content, structure, and feasibility, but both efficacy and effectiveness are not possible to determine following a small-scale test (Leon, Davis and Kraemer 2011). It is for this reason that the current study does not have a hypothesis and rather aims to provide evidence with regards to potential positive effects of intervention development.

The importance for pilot, or feasibility, studies are emphasised in the updated Medical Research Council (MRC) guidance for developing and evaluating complex interventions (Craig et al. 2008). In this regard, complex interventions are understood to have multiple interacting components but a clear distinction between simple and complex interventions is yet to be defined. The guidance for the development of complex interventions delineates three key stages: identifying existing evidence, identifying and developing theory, and modelling process and outcomes. The first of these points related to the expectation that the intervention being developed will actually produce a worthwhile effect. This is accomplished by identifying similar interventions and their evaluations. The second point refers to understanding the changes that are expected, and the third point denotes that the feasibility study should provide the information to inform, if warranted, a large scale version which is amended by the evaluation of the pilot.

The assessment of feasibility is emphasised as a key motive of pilot studies and should focus on acceptability, compliance, retention and delivery of the intervention (Lancaster, Dodd and Williamson 2004). The MRC (Craig et al. 2008) maintain that the pilot study should not be regarded as a scaled-down version of a larger study, but rather to examine key uncertainties, provide insight into areas of potential effect, and the evaluation of the intervention is shaped, but not limited, by this. The use of numerous measurement outcomes requires an understanding of how they will accurately assess multiple outcomes of analysis (Craig et al. 2008; Leon, Davis and Kraemer 2011).

The use of a single primary outcome and a small number of secondary outcomes are recommended, but it is acknowledged that this approach may not be beneficial when the pilot intervention is expected to have wide and effecting multiple domains (Thabane et al. 2010). The aforementioned process evaluation is to identify potential difficulties in recruitment, retention and implementation, but is reported to be insubstantial without evaluation of measurement outcomes. Thus, a pilot study is described by the MRC as a necessary operation in the development of complex interventions to reveal potential positive benefit and to inform the structure, content and evaluation of larger scale studies, in order to ensure their feasibility, acceptability and meaningfulness.

Further guidance for such evaluation of interventions is delineated by the RE-AIM framework (Glasgow, Vogt and Boles 1999) which highlighted the limitation of health promotion, due to the variable levels of the evaluation of intervention assistance. The RE-AIM framework represents five factors: Reach, Efficacy, Adoption, Implementation, and Maintenance in intervention evaluation. These dimensions are to understand the potential population of participants, understand resultant potential changes in behaviour, factors associated with adherence and non-compliance, and longevity of behavioural changes. These guidelines are congruent with the guidance from the MRC as this information is crucial to inform the development of a larger, robust and effective intervention, made possible by such a feasibility study.

A feasibility study is also advantageous due to the complex nature of the intervention set to be developed to meet these criteria. Several studies exist to show the benefit of psychoeducation with caregivers for those with BD (Bland and Harrison 2000; Kim and Miklowitz 2004; Bernhard et al. 2006; Madigan et al. 2012) but do not explore the potential benefits of different intervention components, that could also have beneficial improvements in increasing health and wellbeing beyond the effects of psychoeducation.

2.4.3 Why a Mixed Methods Design is Needed for the Study

The current study utilises a pilot study of mixed methodologies (comprising firstly a qualitative method which derives understanding of the experiences of those caring for a relative with BD to inform the development of a self-care intervention, which is then evaluated quantitatively in accordance with the guidelines provided by the MRC (Craig et al 2008) and RE-AIM framework (Glasgow, Vogt and Boles 1999). Such an approach allows for the development of a targeted, and therefore potentially more effective and robust intervention (Justo, Soares and Calil 2009; Thabane et al. 2010).

2.4.4 Self-care

Self-care can be understood as the engagement with health technologies, with no or little therapist direct involvement, to empower a person in how to help themselves (Lewis, Pearce and Bisson 2012). By providing information on how to change behaviours, attitudes or perspectives, a person can take greater control of their own health in the long term using a method with a comparatively high health outcome-benefit to resource-cost ratio (Weiss 2004). In regards to a pilot study where the level of confounding variables should be as highly controlled as possible, self-care eliminates the potential for interpersonal differences from healthcare workers or experimenters when dealing directly with those in the study (Shapiro, Brown and Biegel 2007). Also, self-care provides a level of anonymity which may encourage more honest feedback with diminished tendencies toward socially desirable responses in the absence of face-to-face interaction with the experimenter (Weiss 2004; Shapiro, Brown and Biegel 2007).

Madigan et al. (2012) show the benefits of therapist led sessions in improving quality of life and reducing distress. The development of a self-care intervention would reduce costs, provide caregivers an opportunity to work in their own time and be readily accessible.

Therefore, to fully understand how best to achieve enhancements in health and well-being in this population, a feasibility study is required to inform the development, deployment and evaluation of such a complex intervention (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002). The benefits of a pilot study will facilitate the understanding of feasibility, acceptability, meaningfulness and effectiveness of intervention assistance (Thabane et al. 2010). Such knowledge will allow for the further refinement of providing help to informal caregivers to alleviate the negative consequences of the role through revealing the potential positive effects of a multicomponent intervention.

Self-care booklets were used in this study to limit the potential confounding variables in the study to ensure reliability (Ogilvie, Morant and Goodwin, 2005). Multimedia interventions have varying levels of effectiveness and the extent of this disparity is thought to arise from content (Kowk 2014). With higher potential of content variability through videos, sound clips, interactive 'click and drag' exercises, multimedia interventions are still too unstandardized for the purpose of this pilot study. The content of the booklet and each of the four components that comprise it are outline later in this thesis for transparency (Kempton et al. 2011).

2.5 Chapter Summary

In conclusion, based on the evidence examined from the literature on burden, carer burden, self-care, and previous intervention research for informal carers of relatives, there is a need to develop a specific intervention for informal carers of relatives with BD. Various limitations have been identified in existing intervention research, highlighting the utility and relevance of the study reported in this thesis. An intervention is required for the caregivers of those with BD as the multitude of psychosocial consequences of their role affects both themselves directly and their ability to deliver care to their relative. The production of an intervention would require understanding of their lived experiences to enable an intervention that is targeted and therefore potentially more effective in addressing issues from their perspective of what works for them (Sörensen, Pinquart and Duberstein 2002; Gellatly et al. 2007).

In order to fully explore the potential benefits of intervention assistance, multiple components should be included to better understand the effect of intervention content, which is the case in the study reported in this thesis. To ensure feasibility of such a robust intervention, a pilot study would be required to assess the feasibility of developed intervention to assess aspects such as participant recruitment, intervention involvement, perceived meaningfulness, acceptability of the content, and also assimilation of contents provided (Thabane et al. 2010; Leon, Davis and Kraemer 2011).

Considering this situation, the present research study sought to gauge the feasibility of enhancing the health and wellbeing of those caring for a family member with bipolar disorder using a mixed methods self-care intervention.

Chapter Three: Research Methodology and Design

3.1 Introduction

This chapter delineates the qualitative research design of the study. The methodology will be discussed demonstrating its utility, and the justification for utilising such a mixed methods approach to the intervention development. Stage One served as the qualitative basis, with Stage Two as the development of the intervention and its assessment, and Stage Three as the quantitative measurement of how effective the intervention was in enhancing health and wellbeing of the informal carers who participated in the study.

3.2. Background of Research Paradigms

Research paradigms can be understood as a collection of assumptions and beliefs to how we view the complexities of the world (Denzin and Lincoln 2001). Paradigms allow us to share our understandings of reality with others, as adherence to sets of assumptions facilitates the exploration, elucidation and dissemination of information in a standardised manner. Such homogenous approaches facilitate a shared view and understanding of reality and are the cornerstones of research methodologies, and the ability to formulate and test theories (Black 1999; Gilbert 2008).

Lincoln (2000) devised a distinction between positivist and naturalist paradigms to reflect the varying approaches they embody. Positivism denotes that reality is a singular construct whereby understandings are created from logical and mathematical reports of sensory experiences of natural phenomena that are governed by natural laws. Conversely, naturalism withholds the view that no singular reality exists, but rather, a multiple constructed and holistic realities, that arise from the perceptions of people in the context of their own lives, and is therefore objective (Johnson and Onwuegbuzie 2004).

Both approaches possess unique and diverse facets useful in understanding the complexities of human experience. The utility of either qualitative, quantitative or both methods together in a study is predetermined by the research question posed, as the uniqueness of each paradigm lends itself to the benefit and detriment of research endeavours through their particular ontological and epistemological congruence with research design (Ponterotto 2010). Qualitative research can be understood to produce a multidimensional understanding of experiences that exceeds common sense awareness, and facilitates a nuanced, informed and empathic practice which differs from the approach of explanation in approaches rooted in the natural sciences (Curry, Nembland and Bradely 2009).

Qualitative Research

Qualitative research can be appreciated as the optimal approach for the exploration of subjective experiences and understanding human perspectives of their own realities (Gilbert 2008), as people and their experiences are multifaceted, and do not always adhere to the logical and predictable outcomes as expected by positivist approaches (Holloway and Wheeler 2013).

Quantitative research

Quantitative research can be understood as validated through its adherence to natural laws and by its very nature is self-validating (Curry, Nembhard and Bradley 2009). Quantitative research can be used to test interventions and provide beneficial pilot data for larger scale attempts (Mantzoukas 2004).

3.3 Sequential Exploratory Mixed Methods Design

The evaluation of complex interventions has been stated to require the use of both qualitative and quantitative evidence (Campbell et al. 2000) and Tashakkori and Teddlie (2003) comment on the variety of approaches to combine both qualitative and quantitative research methods: mixed methods research. The mixed methods research design felt to provide the 'best fit' to address the research question and aim of the current study was a sequential exploratory design (Creswell 2013).

The sequential exploratory design used in this study consisted of two stages of data collection and analysis undertaken in a qualitative, then quantitative sequence (Iavnkova et al 2006) with an intermediary development phase. In Stage One of the study, qualitative data are collected and analysed to give a general understanding of the research problem being explored. This initial stage of qualitative research '*capture[s] essential aspects of a phenomenon from the perspective of study participants, and to uncover beliefs, values, and motivations that underlie individual health behaviours*.' Curry et al. (2009, pp. 1442). In this instance, the phenomenon is that of the experience of providing care for a relative diagnosed with BD. Such a mixed methodological design is recommended for intervention development and evaluation, as the qualitative data can help develop both the intervention itself and also the means by which the intervention can be tested (Natasi et al. 2007).

The qualitative data should be obtained with high regards to rigour and methodological legitimation to ensure that the preliminary data is from a reliable source from which to design a quantitative data collection instrument (Ostlund et al 2010). The qualitative phase of an exploratory design is to provide detailed information of human experience from which to base the quantitative phase of the study (Morgan 2007). This study uses the qualitative data obtained from interviews with the caregivers to inform the design of a multicomponent intervention and its evaluation.

In Stage three of the study, quantitative data were obtained and analysed to provide insight in to positive potential of the intervention developed based upon the findings in stage one. The quantitative evaluation provides more tangible and measurable evidence from which the process of enhancing the health and wellbeing of caregivers of those diagnosed with BD can be further understood The results from both the qualitative and quantitative stages are integrated through a synthesis of the findings to provide a rich in-depth and contextualised understanding of the experience of informal caregivers of relatives in the context of BD (Teddie and Tashakkori, 2009).

The strength of adopting the mixed methods research design is that it can make use of the benefits of each approach (Natasi et al. 2007; Lancaster, Dodd and Smith 2010; Ostlund et al. 2011) In Stage One of the study, the qualitative phase, data from informal care givers were collected via semi-structured interviews with a purposive sample of informal caregivers of relatives with BD, and analysed to identify components of the experience as narrated by the caregivers. Here significant themes from the qualitative findings were identified to help inform the development and testing of a novel intervention. Stage Three, the quantitative phase, involved implementation and piloting of the developed intervention.

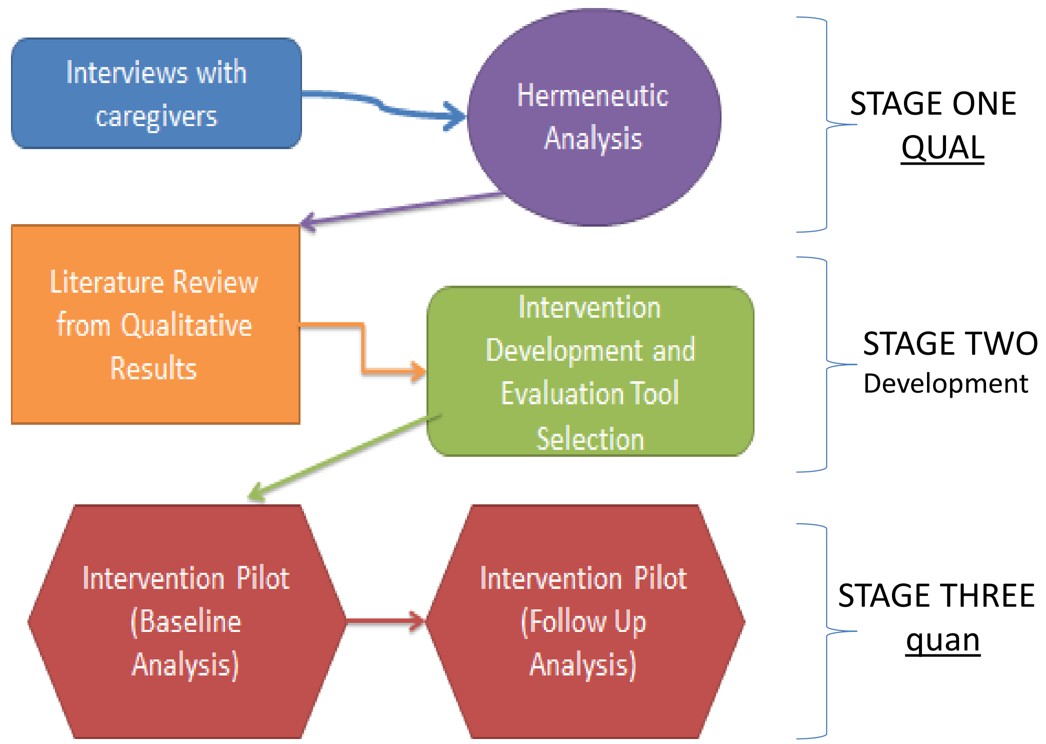


Diagram 1. Model depicting the sequential exploratory design of the study and the three stages. QUAL -> development -> quan is used to represent the weighting of the stages (Morse 1991).

Diagram 1 illustrates the study design to help show the sequence of the qualitative and quantitative methods and the stages at which integration of methods took place (Creswell and Plano– Clark 2007). The QUAL (qualitative) and QUAN (quantitative) terms used in this model come from

Morse (1991) mixed methods notation system. The use of the uppercase and lowercase letters indicate the priority of one methodological part over the other. For example; (QUAL - quan) or whether the weighting applies equally to both (QUAL - QUAN). Nonetheless, there are times when researchers may decide to award different weightings to each design component based on the research aim (Ivankova and Stick 2007).

In sequential exploratory designs, the initial qualitative component of the study is given strong status (QUAL) over the smaller component (quan), as adopted in the case of the current study (Morgan 1998, Ivankova et al 2006). The QUAL status compared to quan is a reflection of the importance of the studies exploration of lived experiences to develop the intervention. The quan phase is still important as it provides the pilot data for the intervention but arguably, pilot data is indicative of potential positive benefit rather than conclusive evidence and for this reason has been considered with a lesser weighting.

3.4 Lived Experience

Lived experience is the main component of qualitative research and refers to the reflexive awareness of the consciousness of life (Dilthey 1985; Van Manen 1997; Casterlé et al. 2011). These lived experiences gather meaning as we attend to them and commit them to memory. The methods of understanding lived experience therefore aim to uncover these significant self-reflections of human lives to make sense of the complexities of individual realities. It is through this open and explorative approach that lived experience is beneficial for the purposes of this study whereby experience can be understood openly to better understand the complex experiences of those caring for a relative with BD.

3.5 Gadamerian Hermeneutic Phenomenology

Hermeneutic phenomenology refers to the extraction of meaning from text (Casterlé et al. 2011). In this study, the process was used to understand the lived experiences of those caring for a relative with BD. The distinction of the Gadamerian approach is summarised with the following aspects of the method:

3.5.1 Intentionality

Intentionality can be understood as *'the internal experience of being conscious of something.'* (Dowling 2007 pp.132) and this process is required to be expressed pre-reflection, and possible mutation of contemplation, to be reported purely (Dilthey 1985; Kafle 2011).

3.5.2 Historicity

Our historicity exists both around and inside of us prior to research enquiry as we are steeped in the constructs of everyday life and what is taken for granted, such as items of use that we are inclined to view purely in their utility; a means to an end (Shalin 2010).

3.5.3 The Hermeneutic Circle

The hermeneutic circle is a process of interpretation whereby understanding is the result of a recurring move between the whole and the parts of a particular focus. In this way, understanding is reciprocal and relies upon the understanding of a given text relying upon reference to constitutive parts and as a whole (Koch 1995).

The reflexivity of the hermeneutic circle ensures those engaging with the text will gain a deeper understanding of lived experience which is detailed by Van Manen as "*the starting point and the end point of phenomenological research which aims to transform lived experience into a textual expression of its essence*." (1997 pp. 36). It is through returning from whole to parts of a text, developing these meanings, that facilitates a deeper comprehension of the lived experience being researched (Kafle 2011).

3.5.4 Fusion of Horizons

When a researcher reads a text they fuse their personal horizon with the horizon of the person speaking in the text which is rich in data in regards to the strength of the spoken word. In doing so, Gadamer argues that they must let go of their own fore-meanings of the phenomena and remain open to the meaning portrayed by the other. In this way, horizons are not static but rather, are dynamic and evolving with involvement in the hermeneutic circle (Annells 1996). Ensuring the fluid state of the hermeneutic circle with credence to the reciprocity of whole and part was intended to remove personal bias as the inclusion of personal fore-meanings would disrupt the process and the hermeneutic circle could not function (Koch 1996; Dowling 2004).

3.5.6 Refutation of Bracketing

A person's prejudice, i.e. their preconceptions and their own horizon that make understanding possible through linguistic experience, were argued to actually facilitate interpretation (Annells 1996; Gruber 2014) and that it was only through language and our historicity we are able to understand (Koch 1996; Shalin 2010). Gadamer asserts that we cannot bracket, or distance, ourselves from these experiences but should be aware of them and how they shape our very understandings (Binding and Tapp 2008; Debesay, Nåden and Slettebø 2008).

The use of descriptive phenomenology, with the use of bracketing, can attribute to the results of Rusner et al (2012). The three themes created using the experiences of caregivers clearly has substance but lacks the clarity of purpose for the needs of intervention development. For an intervention to be effective it must consider the lived experiences of the targeted population and have the process utility to be applicable to intervention development (Sörensen, Pinquart and Duberstein 2002; Justo, Soares and Calil 2009; Gruber 2014).

3.5.7 Universality

This very dynamic process of fusing of horizons between the person expressing themselves and the person understanding is connected by a common human consciousness (Dowling 2007) which Gadamer referred to as universality. Universality is achieved when the two horizons meet and the vantage point of the person understanding changes in regards to the experience linguistically shared by the person being understood (Annells 1996; Applebaum 2012). Such quality of data is required for use in the development of interventions to ensure that they are designed optimally for their intended recipients (Knight, Lutzky and Macofsky-Urban 1993;

Sörensen, Pinquart and Duberstein 2002). To fulfil this optimal design, interventions must be robust, precise and targeted which requires a deep and meaningful understanding of the target population (Walters 1995; Ogilvie, Morant and Goodwin 2005; Justo, Soares and Calil 2009; Gerrish and Lacey 2010).

Considering the limited exploration of lived experiences of those who care for relatives BD, (Goossens et al. 2008; Zendjidjian et al. 2012) it is necessary to engage with this population and explore their perspective of 'being in the world': dasein (Applebaum 2012). Exploring the experiences of a population through phenomenological methods permits a deeper, unbiased accrual of knowledge through the unique detachment that phenomenology embodies (Annells 1996; Kafle 2011). Such means of exploration allows the researcher to fully engage with data from participants and permits the attainment of a higher quality and quantity of data compared to more positivistic measures and even qualitative measures that are still biased through the mutations of their methodologies to suit naturalistic paradigms (Moran and Mooney 2002).

The process of hermeneutics also lends strength to the proposed method as the dialogue from interviews with participants will be transcribed and therefore become texts with potential depth and richness of data (Warnke 1987). This data will require engagement with the researcher to interpret the texts as a prerequisite to understanding (Koch 1996) and following the approach of Gadamer. Although Heidegger (1962) set the basis for hermeneutics in phenomenology the assertions and additions made by Gadamer (1976/ 1998) will optimise the methodology for this stage of the study.

Gadamer's assertion of the importance of language coalesces the tenets of hermeneutics by stating that the language used by people is the most data-rich source of lived experience possible to attain as it is only through the words we use that we can translate our understandings of dasein to share with others (Annells 1996). The capacity to share and mutually understand our lived experiences is framed and shaped by our capacity to actualise these experiences through meaning, i.e. words. Gadamer recognised that language was therefore the epitome of understanding and knowledge (Binding 2008).

3.6 Methodological Legitimation for Stage One

Legitimation has become a valid central issue for qualitative methodologies to ensure rigour and representation are upheld (Koch 1996). A critique of qualitative methods was proposed by Morse et al. (2002) in which the authors argued that there was a high tendency to establish trustworthiness, a term for rigour proposed by Guba and Lincoln (1981), at the end of a study rather than as an on-going process. However, Gadamerian hermeneutic phenomenology relies upon the continual process of validation and authentication of data collected: the fusion of horizons. As discussed earlier, the very nature of the hermeneutic circle relies upon the recurrent process of ensuring congruence between the parts and whole of a text. If a researcher engages properly in the hermeneutic circle, they are engaging in a continuous validation of data throughout the exegetic process (Koch 1995).

The Gadamerian approach further enhances methodological rigour through its attention to detail (Koch 1996), through which a reader should be able to read and make sense of the actions taken by the researcher and any possible influences upon them and the phenomena they are investigating. A research journal allows the researcher to note the means by which their insights are created, shaped and recorded throughout the study and how the study itself comes to be accomplished (Koch and Harrington 1998). It is for this reason that compiling a reflective research journal is an essential component of a hermeneutic process, as it provides a rich data source that can be externally audited for the purposes of determining rigour (Annells 1996).

In regards to representation, ensuring correlation between the researched world and the represented one (Mantzoukas 2004), the reflective journal is also a useful source of legitimation, alongside peer review and ensuring with participants that they themselves feel represented (Moran and Mooney 2002; Morse et al. 2002). The very nature of representation itself is complex in the qualitative paradigms as they refute the foundations of positivism in which there exists just one absolute reality but rather exist *'as plural and will, to a greater or lesser degree, include individual and subjective viewpoints about truth, reality, and what can be learned.'* (Mantzoukas 2004, p. 1000). It is therefore the aim of representation to identify the extent to which the researcher has shaped the research and this impact on the concurrence with lived experience studied and reported.

Gadamer realised the intrinsic nature of the researcher at the centre of research inquiry (Moran and Mooney 2002) and understood the need for a transparent and honest procedure of understanding to limit the bias and influences a person can create knowingly or otherwise. Gadamer's emphasis on language guides the researcher to value the words of participants and utilise these respectfully to keep meaning as intact as possible (Annells 1996). For the present study, the researcher had previous experience in person-centred therapies and utilised the tenets of the approach through empathy, reflection and congruence during the interviews with participants, which encourage self-actualisation in the speaker and facilitate mutual understanding between speaker and listener (Weisner 2014). These aspects of the person- centred approach are consistent with Gadamer's prominence of dialogue and the researcher's own method of interviewing. An alignment of research procedure and the epistemology and ontology of the followed methodology is the crux of representation in qualitative research (Mantzoukas 2004).

The reflective research journal clearly depicts the researcher's process of understanding and construction of the data through the process of the hermeneutic circle. Having this fusing of horizons documented allows for transparency in the process and all conclusions drawn by the researcher should be based in the merging of their horizons with the person of whom the experiences being understood are from (Gadamer 1998). Gadamer also suggests returning to participants once a conceptualisation of the lived experiences has been completed to ensure that their perspectives and experiences are still embodied and communicated by the researcher (Koch 1995).

3.7 Use of Phenomenology in Similar Studies

Chang and Horrocks (2006) investigated the lives and roles of nineteen family caregivers of mentally ill relatives using hermeneutic analysis of transcripts from several interviews per participant to reveal eight major themes. However, the authors only describe three in their publication; the management of day-to-day care, enduring the caregiving process and surviving the care-giving process. The insights provided by these three themes are useful in understanding the experiences of caregivers but apparently withholds five themes claimed to be major elements of the role. Even the three themes that were presented may not be directly transferable due to the oriental culture of the participants and the study of caregivers for persons with generalised mental health conditions rather than BD independently.

Tranvåg and Kristofferson (2008) conducted a hermeneutic study within a western culture with eight spouses/ cohabitants of BD and constructed a journey comprising of fourteen stages to describe the cumulative effects of burden. The spouses were believed to experience up to all fourteen stages as their role as an informal caregiver progressed. The identification of a process and progression through the role of caregiver would be beneficial in intervention work to help identify the care needs of those providing care for those with BD and increase the accuracy and effectiveness of said help. However, a delineated journey of experiences and cumulative burden are not congruent with phenomenology by its very nature.

Despite the benefit of producing a journey of possible experiences, the very essence of phenomenology would stress that it is the subjective experiences of these processes that would create the ‘life worlds’ of those living them and that the perceptions of each individual would be unique through their own perspectives (Taylor 1993). By placing the impetus of the findings on a process, the experiences of the life-worlds are constrained and efforts to utilise this process in evidence based practice could overlook aspects of the lived experiences due to the structured dissemination of findings but still shows the advantages of a phenomenological approach nonetheless. Using a Gadamarian approach would not allow the results to be structured in this way and confine lived experiences to a uniform process whereby creating the potential for the hermeneutic circle to be 'open' (Caton and Santos 2008) and incomplete, i.e. not fully having explored the phenomena.

In 2009, Champlin (2009) interviewed twelve caregivers of relatives with unspecified chronic mental health conditions and using interpretive phenomenology, found eight themes: accepting the changed other and grieving the loss of who the other was, taking action in challenging circumstances, recognising the on-going nature of the experience, isolation, tension, knowing and caring for the care recipient and 'ambiguity of the heart' which referred to uncertainty of caregiving actions. Such a variety of themes displaying the effects of the caregiving role for a person with any mental health condition reflects how the consequences of caring can be similar. However, the exploration of caregivers for individual conditions may have provided specific differences based on the care receiver's illness and facilitated a more specific understanding of caregivers experiences rather than as a general population. In regards to those caring for relatives diagnosed with Bipolar Disorder, the role may be unique by comparison to other mental health conditions so reliance upon generalised results could limit the utility of the findings in regards to informed intervention development (Ogilvie, Morant and Goodwin 2005).

Such a focus with caregivers of relatives with BD was undertaken by Rusner et al. (2012) where the transcription interviews of twelve people within said population were analysed using 'phenomenological meaning-oriented analysis'. Three overarching themes were elucidated: Struggling for Survival, Having to Compensate, and Being Both One Step Ahead and One Step Back. Struggling for survival was understood as survival for their care receiver and for themselves. Survival for the care receiver oriented around dealing with the views of family and friends and encouraging adherence to treatment plans.

Self-oriented survival regarded being heard by health professionals, dealing with changes to the future, and creating a balance between the identity of being a caregiver and being a relative. Having to Compensate was understood as the misunderstandings of others in regards to what they were going through, observing the vulnerability of their care receiver and learning to adapt to the role and life changes of a caregiver. Being Both One Step Ahead and One Step Back referred to being constantly attentive of the care receiver's health, providing emotional support to their relative and the balance between caring for the self and their relative.

The data reflects the plethora of challenges faced by those providing care for a relative with BD and encapsulates many well documented consequences such problems dealing with healthcare professionals (Maskill 2010), providing support to follow medication regimes (Sajatovic 2006), balancing self-effacement and self-fulfilment (Van der Voort et al. 2009), and constantly observing the health of their relative (Shah, Wadoo and Latoo 2010) for example. However, considering the unobtrusive and open nature of phenomenology, we would expect to see a more holistic view of lived experiences and the authors fail to note any positive consequences which are documented for both caregivers in general (Koerner, Kenyon and Shirai 2009; Brouwer et al. 2005; Hunt 2003), in mental health (Bauer et al. 2012), and BD (Maskill et al. 2010). An omission of such a documented component suggests an incomplete engagement with the hermeneutic circle (Debessay, Nåden and Slettebø 2007) and indicates the potential for further exploration and could explain the wide and encompassing themes. Further engagement in the hermeneutic process may have broken these three themes in to further constituent parts that could have provided a deeper understanding of the phenomena and provide more specific understandings from which to develop targeted interventions.

Rusner et al. (2012) relied upon a lifeworld phenomenological approach, although the inclusion of the term 'lifeworld' in the name seems redundant as the premise refers to Husserl's description of the world that is experienced directly by a person including individual, perceptual and social experiences, and is therefore a crux of a phenomenological approach (Finlay 2011). The study was also conducted using the phenomenological methods of Merleau-Ponty, a derivative of the Husserlian approach that relies upon the premise of bracketing and perception of phenomena rather than the experiences of them. The exploration of the lifeworld of a population would therefore be better suited to an approach that accommodated the allowance of experiences to be recognised, such as the Heideggerian or Gadamerian approaches that utilise an ontological approach to extract experiences. Reflection is key in hermeneutics as the lifeworld itself is understood in reference to itself and not just solely upon a static perception but upon deeper contemplations and personal interpretations.

A need for ontologically concerned phenomenology, i.e. focused on reflective beliefs, is also seen in the results of an interpretative phenomenology study (Wilkinson and McAndrew 2008) that elucidated the themes of Powerlessness, Feeling Isolated, A Need to Recognised and Valued, and a Desire for Partnership from the experiences of caregivers of a relative with a mental health condition. Akin to the study by Rusner et al. (2012), the data drawn from the experiences are useful in further understanding the lives of those providing informal care but do not reflect a holistic representation of the experiences and indicate incomplete analysis (Annells 1996: Applebaum 2012).

3.8 Stage One Research Question

This aim led to the research question: What are the experiences of those who provide care for a relative diagnosed with bipolar disorder?
The findings elicited from this research question contributed to the Stage Two development of the intervention.

3.9 Stage One Ethical Considerations

Ethical approval was sought from the relevant research ethics committee of the School Ethics Research Panel for the Nursing Department at Robert Gordon University prior to starting the study, including negotiation of access to relevant care support groups and organisations. Information sheets and consent forms (Appendices 1 and 2) were provided to each participant along with a face-to-face detailed explanation of the study, including voluntary participation, withdrawal and confidentiality. Participant contact with carer services allowed for prior knowledge and understanding of these resources in the event that anyone taking part would wish to utilise these services.

Participants were given a debrief sheet (Appendix 3) which included contact details of the researcher and information of local carer services that were made aware of the study prior to operations to ensure that any needs that may arise from participation in the study could be met and dealt with efficiently from appropriate pre-informed services. All data collected was analysed, anonymised, reported and held securely in accordance with the Data Protection Act (1998) and Robert Gordon University Research Ethics Governance (2014).

With regards to the potential sensitive nature of the research the participants were not re-approached to verify the hermeneutic analysis in a follow up once the analysis was complete, as is suggested in Gadamerian approach (Gadamer 1998; Austgard 2012). This was to avoid subjecting participants to possible discomfort as the nature of what they discussed could at times be difficult and affirming the conceptualisations of their experiences have the potential to be a negative experience (Lee 1993). Engaging in an interview of any kind where the nature of the focus is sensitive, those being interviewed may find the experience cathartic but secondary and subsequent encounters with the same topic or researcher can disrupt this process (Liamputtong 2007).

Re-experiencing the disclosure of sensitive issues can coerce participants to relive negative thoughts or feelings that may have culminated following interviews (Lee-Treweek and Linkogle 2000). If a person has not had the opportunity to talk openly and honestly prior to being interviewed, they may require time to reflect and re-adjust in the time following this experience and should be regarded as more vulnerable whilst this process occurs (Lee 1993; Liamputtong 2007).

For the researcher, the University counselling services were made aware of the study should they wish to contact them and continual debriefs with the supervisory team were made available.

3.10 Stage One Procedure

3.10.1 Gaining Access

Six informal caregivers of relatives with BD living in the Grampian region of Scotland were recruited to participate in the study; three through contact with local carer services and three through opportunistic word of mouth. Those recruited from carer centres were contacted via a stated liaison for each organisation who was informed of the study and made those who fit the participant criteria aware of the opportunity to participate and presented them with an information sheet and contact information of the researcher.

Initiating contact via patients with BD was not selected as a recruitment method as the caregivers may have felt obliged to take part if their care recipient approached them with the opportunity and could be construed as coercion (Eldridge and Kerry 2012). Recruitment within the hospitals were limited to designated carer support areas and not outwith as caregivers visiting hospitals may be there under strenuous or stressful situations such as care recipient diagnosis or re-admission. Such events exert a high degree of burden for caregivers and attempted recruitment at such a time would violate non-maleficence (O'Mathúna 2012).

Those recruited through opportunistic word of mouth were those who had heard of the study through indirect means such as friends of colleagues of the researcher. They too were provided with an information sheet and contact information through their personal connection. All participants who wished to take part initiated contact with the researcher and were then provided with the opportunity to ask any questions. A mutually agreed upon date, time and location for their interview was then established.

3.10.2 Sample Population

All participants were purposively sampled as informants for studies investigating lived experience are concerned with a particular phenomenon (Newing, Eagle and Puri 2011), in this instance the phenomenon of interest was the experience of providing care for a relative with BD. Therefore, those with such experience were targeted as the intercept population.

Six informants who met the inclusion criteria were interviewed for the purpose of the study. Four participants were female and two male with a mean age of sixty four. Four participants were spousal caregivers and two provided care for adult children. The diagnosis for the care recipients varied between ten months and thirty years. All participants recognised themselves to be white English speakers and provided informed written consent prior to engaging in the study.

3.10.3 Data Collection and Engagement

The semi-structured interviewing method was selected as it enables participants to articulate their experiences from their own perspective, allowing the researcher to examine the phenomenon in context, and to generate a deeper understanding from the participant's own accounts of meanings attributed to their experience, as well as understanding their own framework of reference. Structured interviews would not allow for an in-depth response as they are overly restrictive in structure, and an unstructured interview could fail to guide the participant enough when responding to questions leading to digression (Ayala and Elder 2011).

The semi-structured intercept interviews were constructed to subjectively evaluate the views, experiences and difficulties experienced by informal carers to ensure that data collected could contribute to a more person-centred solution focused intervention which is reported to yield a greater effectiveness compared to an objective approach (Chambers, Ryan and Connor 2001).

Participants took part in individual semi-structured in depth interviews that lasted between forty-seven and eighty minutes with a mean length of fifty-eight minutes in a private room at the Robert Gordon University except for one participant who requested a private location close to their home as their own health limited the ability to travel. All participants were offered the choice of being interviewed at the university, in their own home or another location of their choice where they felt they had privacy to talk. No hand held notes were taken during the interview to ensure that participants felt respected and attended to (Mearns and Thorne 2007; Gerrish and Lacey 2010) however the researcher filled out notes in a reflexive journal following each interview to ensure that thoughts and feelings were captured imminently. The following is an excerpt from the researcher's journal written after an interview to illustrate the early stage of data engagement:

> 'Julia (Pseudonym) was so open and honest about her experiences that it's really humbling to speak with her about them. When she spoke about no longer recognising her husband and how she sees him fading away, it was almost like talking to a widow. She did speak of more positive things too though and it's quite incredible how she's adapted to the role and it sounds like her life is one big military operation. I'm really glad that I've had experience in talking to people who have experienced hardship as I think otherwise I would have been prone to trying to comfort her while she spoke, tell her everything was okay. My heart really goes out to this woman. I suppose that such a moving story can provide a lot of good data. I hope the end product of this study does justice for people like her. Dickson-Swift (2007) mentions the feelings of privilege following listening to such an experience and this rings true for how I feel right now.'

In this instance, the study of previous literature contributed to the development of the interview schedule used (e.g. Dore and Romans 2001; Deekan et al. 2003; Brouwer et al. 1999; Goossens et al. 2008; van der Voort, Goossens, and van der Bijl 2009) (See Appendix 4) to ensure that appropriate questions were asked (Gadamer 1998). The schedule was also piloted with two people who had been informal caregivers to a person with BD. This led to a rewording of two questions in regards to lexical complexity and omission of one question that appeared to be too open-ended due to individual interpretations of what the question was asking. This refinement following the internal piloting of the schedule is consistent with Gadamer's assertion of asking the right questions (Koch 1996). In alignment with the importance of language used to form the spoken word of the person being understood, the researcher must ensure that the words they use are congruent and consistent with their own intentions to reduce ambiguity between those in the dialogue (Gadamer 1976).

Prior to audio recording the interview, the researcher introduced himself, the purpose of the study and ensured the participants were informed and consented to continuing. Each participant was asked the questions from the interview schedule throughout their interviews but beyond this structure participants were encouraged to talk in depth about their own experiences and perceptions of their role. Open ended questions and reflection were used to facilitate the participants and consequently gain a richer verbalisation of their perspectives (Platt and Gaspar 2001).

Open ended questions can encourage someone being listened to and to elaborate beyond affirmation and refutation of closed questions (Curwen, Palmer and Ruddell 2000). Reflection is also a very beneficial method whilst undertaking interviews as rewording of what a participant has said and saying it back to them in your own words allows them to accept or decline this personal interpretation. This validates the fusion of horizons or allows for the researcher to be corrected and realigned with the participant's own horizon (Mearns and Thorne 2007). The process of reflection also allows a person being listened to, to recognise that they are being understood which can facilitate the process of self-actualisation and lead them to report greater content and quality of lived experiences (Platt and Gaspar 2001).

The interviews were digitally recorded and transcribed (See Appendix 5) then dwelled with repeatedly by the researcher to facilitate a deep understanding of the experiences of the participants (Koch 1996). At this point, the first stage of analysis was operated through NVivo 9 to manage the volume of generated data and make sense of it. Dwelling with data is an integral component of hermeneutics as the data is so rich that experience and familiarity with the texts are a required first step to ensuring that the horizon of the researcher can be open and receptive to change, allowing the accrual of understandings through fusing their horizon with that of those listened to (Dowling 2007; Finlay 2011; Kafle 2011).

Key themes were identified and quotes from the scripts were placed accordingly within a categorising structure. These quotes were then read in their themes and the transcripts were re-read to ensure that the data still made sense and were congruent with individual interpretations for each participant (See Appendix 6). By collating quotes that share meanings and grouping them, the researcher is able to conceptualise a facet of lived experience. This method facilitates the re-structuring of the experiences heard by the researcher from their core components to create a meaningful and holistic understanding (Applebaum 2012).

From transcription to engaging with the individual interpretations and whole transcripts, the process in its entirety is to engage within the hermeneutic circle (Annells 1996; Fleming, Gaidys and Robb 2003; Debesay, Nåden and Slettebø 2008). The lived experiences of the participants can only truly be understood in this way as a fusion of horizon can only occur when the researcher opens themselves to the new experiences and understands them in their own way, through which their own horizon is re-shaped to a new way of understanding (Van Manen 1997; Finlay 2011). Engagement in the hermeneutic circle resulted in the combination of two minor themes and the omission of three other minor themes due to levels of overlap and low concurrence between responses between participants regarding these themes.

Following the amendments made to ensure the reciprocity of the hermeneutic circle, the remaining themes were conceptualised with representative quotes from the participant transcripts and these themes were then organised in to a conceptual model to reflect the lived experiences of those caring for a relative with BD. The participant transcripts, individual interpretations and quotations organised in to the major themes were then re-dwelled with to ensure that they remained congruent with the conceptual model and the hermeneutic circle was uninterrupted (Gadamer 1998; Binding and Tapp 2008). It is important to check fit with the hermeneutic circle and all stages of data accrual, processing and reconceptualisations to enhance the methodological legitimation of the study and producing valid and meaningful results (Annells 1996; Koch 1996; Prasad 2002).

The verification of accuracy of findings was fulfilled through keeping a reflective journal during the exegetic process to delineate the interaction with the hermeneutic circle for transparency of engagement with the data (Cohen, Kahn and Steeves 2000). The following excerpts from the researcher's reflexive journal exemplify reflections at various stages in the hermeneutic process.

> 'There is so much data, every day I find more and more aspects of the role. The first to categorise was that of the support that the carers provided. There are so many emotions running through the texts that it's easy to remember exactly *how* the participants sounded. It's a strange experience but the more I read and reread these transcripts the more the process is starting to make sense.' – Initial dwelling with transcripts.
>
> 'I've had to take out the minor theme of physical pain from the categories as not enough evidence supports this. Also, for the positive aspects I feel that I may have more than three. I have two regarding the care and strength of the CR [care receiver] but personal growth seems to be outgrowing itself. I feel that finding meaning and recognising change in oneself are distinct.

> The former is seeing what is good and appreciating it and personal change is the adaption to the role, almost like a learning experience. This seems to fit with the transcripts too when I re-read them, especially the areas in which the carers talk about the positives, even if they were reluctant to recognise any when first asked.' – Development of categories, in particular the perceived positive aspects of the role.

The process was followed and affirmed by a secondary researcher experienced in the use of Gadamerian phenomenology and hermeneutics (Gadamer 1998) who had access to the participant transcripts, the conceptual model created of the entire process and the individual interpretations. Such secondary confirmation of findings is necessary to add legitimacy to the use of hermeneutics to ensure that the researcher has not misinterpreted data or imposed their own opinions or thoughts in to the findings, consciously or otherwise (Finlay 2011).

A Summary of the Qualitative Analysis Process in Stage One is provided below:

1) Semi-structured interviews with participants recorded.
2) Reflexive journal written on and after interviews to capture thoughts and feelings regarding informal carers experiences listened to.
3) Listening to recordings and transcribing interviews.
4) Dwelling with the data to initiate fusion of horizons.
5) Collating of major themes using NVivo 9.
6) Re-reading transcripts to ensure fit of major themes.
7) Grouping quotes from transcripts in to major themes to form minor themes.
8) Using reflexive journal to document these decisions and processes.
9) Ensuring major themes and transcripts are congruent (hermeneutic circle).
10) External validation of process with secondary affirmation.

3.11 Stage Three Design of Research Study

Stage Three involved the quantitative assessment of the intervention pilot based upon the difference in the health and wellbeing outcomes between the intervention and control group.

3.12.1 Stage Three Aim

The aim of Stage Three was to pilot the developed intervention gauging feasibility, acceptableness, meaningfulness, and effectiveness to enhance the understanding of how best to assist those caring for relatives with BD through self-care. This aim led to the research question below.

3.12.2 Stage Three Research Question

Which methods of self-care are evaluated and reported to enhance the health and wellbeing of caregivers of a person with bipolar disorder? Exploration of the four components separately rather than as a whole allows understanding of the effects of each component rather than a uniform score which could resort in both false positive or false negative effects (Gillan, Dodd and Williamson 2002).

3.13 Stage Three Ethical Considerations

Ethical approval was sought from the relevant research ethics committee of the School Ethics Research Panel for the Nursing Department at Robert Gordon University prior to starting the study, including negotiation of access to relevant care support groups and organisations. Participants provided informed consent prior to taking part in the study. All those involved were informed that their participation was voluntary, that they could withdraw at any time without reason, that all information would be kept confidential and that the intervention was not in place of existing or future assistance from healthcare professionals.

Participants were provided with the contact information: postage address, telephone number, and e-mail address, of the study primary researcher and prompted to contact at any time with any questions or queries. All data collected was analysed, anonymised, reported and held securely in accordance with the Data Protection Act (1998) and Robert Gordon University Research Ethics Governance.

3.14 Stage Three Procedure

3.14.1 Gaining Access/ Recruitment

Initially, forty nine carer centres were contacted across the UK: sixteen in Scotland, twenty seven in England, four in Wales and two in Northern Ireland. Carer centres were listed by the Prince's Carers Trust and of those groups who had contact information, an e-mail was sent outlining the study and asking that anyone they knew fitting the criteria of caring for a relative with BD could be made aware of the opportunity to participate. Furthermore, the study was advertised on the Robert Gordon University home page with information about the study and contact details of how to enquire about taking part. This release was later advertised on caregiver websites and in several newspapers in the Aberdeenshire area with varying levels of detail regarding the study depending on article length and how to take part.

Participants were not recruited through the NHS as this would have relied heavily upon relatives as a mediating factor on whether they wished for their relative to know about the study or not. Inclusion of such a subset should be considered for larger scale attempts (Leon, Davis and Kramer 2011), but for the purposes of the pilot study reported in this thesis, caregivers were themselves given the choice when the study was freely advertised. However, it should be considered that gatekeepers at carer centres may have influenced who was aware of the study selectively, even though they were advised not to do so in communications with them.

Participants contacted the primary investigator through their preferred means and were given an information sheet and consent form that outlined the study and what would be expected of them (Appendices 9 and 10). The caregivers were asked to reply with a delivery address if they wished to take part in the study. Each participant was assigned a unique number and placed in the control and intervention group on a 1 to 1-2 basis, whereby one third of recruited caregivers would be placed as the control group and two-thirds were placed as the intervention group. With relatively high dropout rates in longitudinal complex intervention studies (Deekan et al. 2003; Christensen, Griffiths and Farrer 2009), it seemed necessary to recruit in this manner to allow for similar numbers to remain in each group post intervention. As the ethos of the study was to pilot the intervention, a heavy emphasis on gaining information on intervention experience was the focus and required a higher number of participants (Lancaster, Dodd and Williamson 2004; Craig et al. 2008).

3.14.2 Sample Population

Forty participants agreed to take part in the study following contact and received an information sheet. Four did not complete the baseline analysis with one declaring their time was too taken up by their caregiving role, and no response from the other three. Therefore, at baseline, twenty six caregivers were in the intervention group and ten in the control group. Sample size calculations were not performed as the pilot study aimed to provide positive potential indications of benefit to inform a larger scale study which would require such a calculation.

The majority of caregivers recruited lived with their care receiver, were spouses, female, and did not state any personal mental health conditions. Their ages ranged from thirty six to seventy years old with a mean age of just under fifty-three years. These demographics are consistent with recruited populations in other BD caregiver studies (Jönsson et al. 2011; Madigan et al. 2012). On average, the length of time the care recipients had been diagnosed with BD was almost sixteen years, with the caregivers having known them for on average just over fifteen years during this time. The majority of reported studies on caregivers have been reported as female, spousal caregivers who live with their care receiver.

3.14.3 Intervention Pilot

Once participants had read an electronic or posted hard copy of the information sheet, if they wished to take part in the study they provided a delivery address for posting their intervention package to be delivered. The intervention package contained: (i) the 118 page intervention booklet (detailed in Chapter 7), (ii) a booklet containing the self-report assessment tools (detailed in Chapter 8) including sociodemographic questions, (iii) a copy of the information sheet, and a consent form

(Appendices 8 and 9), (iv) and a pre-paid freepost envelope. The consent form and assessment booklet were marked with each participants unique code to facilitate data handling. The caregivers were asked to re-read the information sheet, complete the consent form if they were still willing to take part, and send this and the completed assessment booklet back in the envelope provided when they were ready.

Upon sending off their envelope, participants in the intervention group were then given four months to work through the intervention booklet. The control group did not receive an intervention booklet in their packet. When two weeks had passed with no response, a follow up e-mail enquired whether participants were still interested in taking part. Only five participants required follow ups, with one other participant replying to say they would post their envelope soon. One dropped out stating heavy caring commitments, and three did not reply and therefore were not included in the study.

At four months from receiving a first response, a second packet was sent to participants containing the same assessment booklet from baseline, a pre-paid return envelope and a debriefing thank you letter (Appendix 11) for taking part were included. Similarly, after two weeks a follow up response reminded participants of the study and that continuing was voluntary. Ten responses were sent and of these ten, there were no replies and continued participation was assumed to have ceased. One of the participants contacted did however send their response booklet back but after four months and the inclusion of the data was deemed as confounding considering the extra time that would have allowed for either further assimilation of information from the intervention or a depletion of the skills attained.

3.14.4 Data Handling and Management

When the envelopes containing the first assessment booklets and consent forms arrived, their data was input according to their unique code in to an Excel spread sheet. A secure file was kept that contained participant details according to their unique code so that follow up assessments could be delivered. Responses for assessment tools were input in to pre-programmed Excel sheets that would calculate scores efficiently. These Excel sheets were tested against the scores derived from the first four assessment booklet responses marked by hand, to ensure accuracy.

All assessment tools were self-reported and printed in paper booklets (For the benefits of the self-care design of this study, see section 2.5). The Understanding Mood Disorders Questionnaire asked for agree/disagree responses to statements about mood disorder and select symptoms for manic and depressive phases. The Automatic Thoughts Questionnaire and Positive Automatic Thoughts Questionnaire asked participants to rate the prominence of possible automatic thoughts based on frequency of experience. The Social Support Questionnaire gave participants social situations and asked them to rate the number of people they could rely upon in these situations and also to evaluate the level of content they had with this number. The Five Facet Mindfulness Questionnaire asked participants to rate statements relating to mindfulness using a five-point Likert scale. The Warwick Edinburgh Wellbeing Scale also used a five point Likert Scale with statements regarding wellbeing. The Jalowiec Coping Scale gave examples of different means of coping and asked participants to rate how often they relied upon and also their perceived effectiveness of such methods. The Dispositional Resilience Scale used a four point Likert scale and asked participants to rate the validity of statements regarding perceptions of personal experiences.

3.15 Chapter summary

The study used a sequential exploratory design adopting qualitative (hermeneutic phenomenology) method to gain insight and provide understandings of the lived experience of the targeted population, to inform the design and evaluation of a multicomponent intervention. The intervention was piloted longitudinally and differences between the intervention group and the control group at follow up, were used to gauge the potential positive benefit of such intervention assistance.

Chapter Four: Development of a Multicomponent Self-Care Intervention

4 .1 Introduction

This chapter describes the development of the multicomponent intervention devised and piloted in this study. Self-care is introduced and the components for the developed intervention are justified using the results from Stage One and previous literature. The intervention comprises of a psychoeducational, a cognitive behavioural, a social skills and a mindfulness component.

4.2 Search Strategy

Searches to identify relevant articles based upon the findings of stage one and in relation to intervention development was conducted using a combination of subject headings such as 'psychoeducation', 'behavioural', 'social (skills)', 'mindfulness' were combined with combinations of 'self-care', 'informal care(r)(ing)', 'bipolar disorder', 'care(r)(giver) burden', 'experiences', 'relatives', 'home care(r)', 'coping' and 'intervention(s)'. Databases searched were ScienceDirect, Medline, OVID full text journals and PsychINFO. This search strategy provided 118 journal articles and 14 books, one of which could not be located beyond a citation. Further reading was supplemented with hand searching of psychology, social work, nursing and psychiatry journals and relevant books that cited in the articles found.

4.3 Self-Care as an Intervention Strategy

Self-care is widely accepted as an integral component to maintaining health and preventing disease but the definition of what self-care is varies from compliance with treatment regimes, the ability to initiate and complete activities of daily living, and managing and reporting symptoms of ill health (Lubkin and Larsen 2005). Little or no therapist input is used in self-care, rather the person engages in health technologies to facilitate self-improvement (Lewis, Pearce and Bisson 2012). The benefits of self-care include the cost-effectiveness of providing healthcare technologies without the resources required for therapist interaction and a higher level of perceived anonymity so that those involved will be more open without feeling judged or threatened (Weiss 2004). The limitation of self-care would be that without the personal dynamic of a therapist, great efforts must be undertaken to achieve delivery and content that facilitates interaction (Craig et al 2006).

Relating to health behaviour, primary prevention refers to behaviours and actions taken proactively to maximise well-being, and secondary prevention is reactive to specific illness or health risks (Martin, Haskard-Zolnierek and Dimatteo 2010). Both primary and secondary prevention self-care methods are necessary to allow informal caregivers to both negate negative effects of the role, such as psychosocial detriment (Maskill et al. 2010), whilst enhancing positive aspects such as caregiver satisfaction (Cohen, Colantonio and Vernich 2002; Hunt 2003).

The process of self-care can be difficult to maintain and achieve, this is reflected in low rates of low adherence and high dropout rates in treatment plans (Christensen, Griffiths and Farrer 2009). To combat this, self-care should be framed in such a way to empower the targeted population in how to achieve goals and increase their beliefs in their own abilities, i.e. self-efficacy (Newman, Steed and Mulligan, 2004). Many self-care programs include symptom identification, self-monitoring, evaluating coping styles, seeking adequate and appropriate support, managing the impact of illness on social relationships, and daily functioning and emotions (Hinds et al. 2000; Schreurs et al. 2003).

Self-care has been shown to be effective for depressive symptoms (Cuijpers et al. 2011) and is suggested to be beneficial for relative caregivers as they lack the time to attend intervention groups or support external to their central point of care provision (Knight, Lutzky and Macofsky-Urban 1993).

It has been theorised that many of the negative consequences associated with providing care to an unwell relative may be caused through a lack of meeting one’s own needs (Acton 2002). Burton et al. (1997) compared those caring for relatives with non-caregivers and found that caregivers were at increased risk of lack of sleep, forgetting to take prescriptive medications, lacking time to exercise and having insufficient time to recover from illness; all of which are related to self-care behaviours. Furthermore, caregiver burden and stress have been shown to be inversely related to practicing health promoting behaviours (Burton et al. 1997; Sisk 2000; Lu and Wylke 2007), which shows that the more overwhelmed or unprepared a caregiver is, the less likely they are to try to make themselves well.

Healthcare professionals are therefore less likely to come in to contact with those who are of higher need of care as their focus of care provision when perceiving high levels of burden remains upon their care receiver (Burton et al. 1997; Acton 2002). As those caring for a relative with BD experience relatively higher levels of burden and related psychosocial outcomes (Maskill et al. 2010), they are of an increased need for the implementation of self-care behaviours.

4.4 Interventions

An intervention is a program designed to elicit changes in a person's health status through behavioural or psychological change (Nolan, Grant and Ellis 1990; Haskard-Zolnierek and Dimatteo 2010). The first theoretical model regarding behaviour change was the Health Belief Model (HBM), developed in the early 1950s that described personal attitudes and beliefs as the moderating factors of engaging in health orientated, or self-care, behaviours (Rosenstock 1990). The HBM however, did not account for other factors that could influence health behaviours such as their intentions based on perceived personal goals, awareness of health issues, motivation, perceived choice of actions and personal control which led way to numerous further models such at the Transtheoretical Model of Change, Theory of Planned Behaviour, Information-Motivation-Strategy Model (Martin, Haskard-Zolnierek and DiMatteo 2010). Whilst the models overlap and expand upon each other, they all agreed that interventions required understanding of many facets and consequences of the lives of the intended recipients.

Ways in which to optimise the insight in to moderators of the effectiveness of self-care have been undertaken but have failed to provide a comprehensive description of them (Schreurs et al. 2003) . Despite this, there is still an on-going recognition of the necessity for multi-component interventions (Holdsworth et al 1994; Gellatly et al 2007). The development of interventions for caregivers has been evaluated and critiqued in several studies, all of which provide guidance for increasing intervention effectiveness and robustness.

In 1993 Knight, Lutzky and Macofsky-Urban conducted a meta-analytic review on caregiver interventions from 1980 to 1990. It was discovered that psychosocial and respite based interventions demonstrated moderately strong positive effects on caregiver distress which was treated by the authors to include subjective burden, anxiety, depression and hostility. Critiques regarding intervention development arose regarding selection of participants, lack of representative comparison groups, use of unjustified or inappropriate measurement tools, incomplete reporting of outcomes and the unjustified types of intervention implemented (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002).

Participant selection and group allocation were highlighted as areas of potential confounding influence through the means by which they were recruited. It was recognised from the studies selected in the papers included that participants were being selected as a homogenous group when they should be regarded as unique in relation to individual variables. Differences in the perception of the caregiving role and effects of outcome have been reflected to be affected by gender (Pinquart and Sörensen 2006; Morse et al. 2012), cultural background (Morse et al. 2012), and relationship to the care recipient (Pinquart and Sörensen 2011; van Groenou, de Boer and Iedema 2013). If these factors are not recognised, the effectiveness of interventions may be masked by the varying outcomes of these groups.

The authors argue that participants should not be allowed to self-select in to an intervention or treatment groups, as a predisposition for seeking assistance could populate the sample with overly enthusiastic volunteers, who would be less likely to drop out and more likely to report enjoying the intervention. This observation was supported by Gellatly et al. (2007) who found that interventions were more effective with caregivers when they were eager and confident to participate compared to those who were not.

The issue of measurement tools used to evaluate interventions focused on selection of means that were unjustified. This resulted in high rates of use of non-validated and unreliable assessment tools. The authors note how this may mask the effectiveness of interventions as poor measurement can lead to attenuation, which can be controlled for, but was not done in the majority of studies. The sensitivity of measurement tools was also brought to focus with the example of a popular assessment tool for burden; the Zarit Burden Inventory (ZBI: Zarit, Reever and Bach-Peterson 1980) was relatively insensitive to change. The ZBI was defended in regards to sensitivity as a two strain measure: role strain and personal strain (Whitlach, Zarit and Von Eye 1991).

This defence furthers the argument of poorly justified intervention assessment tools of Knight, Lutzky and Macofsky-Urban (1993), as most interventions studied did not focus on changing the role of the caregivers and therefore the changes in personal strain would be masked. The use of more commonly applied and tested measurement tools is recommended to enhance the generalisability of intervention studies (Craig et al. 2008). Also, considering that burden is not definitively conceptualised (Chou 2000), for results to be generalisable what is being measured must be standardised and therefore delineable. With multifarious constructs such as burden, it is less possible to produce meaningful and clear results of interventions rendering their perceived effectiveness limited.

The employment of varying and unjustified methods of intervention is the final critique outlined in the paper. The selection of approaches in the evaluated studies is described as arbitrary and unjustified. Sörensen, Pinquart and Duberstein (2002) further outline this methodological flaw arguing that certain outcomes may be more/less sensitive to certain intervention types, and that individual differences of participants may make them more or less likely to adhere to different forms of intervention. This would indicate that certain factors can influence which types of intervention people respond best to, and that adherence to certain interventions can have varying outcomes. The reported lack of strong effect across multiple attempts at interventions is possibly attributable to these guidelines not being recognised or adhered to. For example, in a recent paper by Mackenzie et al. (2013), the authors recognise that several meta-analyses of caregiver interventions question their effectiveness. However, the authors limit their target population to caregivers with clinical levels of distress despite this sample being both unrepresentative and narrowly focused on just one of many symptomological outcomes.

Furthermore, the authors recognise that many caregivers consequentially experience cognitive impairment which leads to an increase in perceived stress, as reported by Vitaliano et al. 2011, yet only recruit participants who are measured as cognitively competent for their age. For interventions targeted at caregivers to progress to clinical effectiveness, efforts must be made to not just recognise, but also adhere to the constructive criticisms of previous attempts.

Nolan, Grant and Keady (1996) suggest three categories of consideration for intervention assistance for caregivers: dealing with events/problem solving, finding alternative perspectives of situations and dealing with the symptoms of stress. Such an approach is aimed to treat caregivers as individuals in their own right, respecting the uniqueness of each situation that arises through the complexity of perceived aspects of the role. An intervention must be developed in such a way that experiences of those that the intervention is developed for must be understood and appreciated (Giorgi 2005; Smith 2007).

To meet the predefined criteria of a robust intervention, the design would have to be informed by the lived experiences of informal caregivers, be developed in a way to incorporate a multicomponent design to explore the effects of different intervention types with the structure and content of these to be apparent, control for confounding variables and make use of standardised and validated measurement outcomes to explore the components of the experience, rather than using global scoring measurements (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Habil and Duberstein 2002; Ogilvie, Morant and Goodwin 2005; Montgomery 1996; Reinares et al. 2006; Goossens et al. 2008).

From the exploration of the lived experiences of the informal caregivers from Stage One of this pilot study and the literature evidence reviewed were integrated and informed, the four types of interventions selected to provide the best fit, regarding the requirements for preventing negative consequences whilst enhancing and maintaining the positive consequences. These selected intervention methods were (i) psychoeducational, (ii) cognitive behavioural, (iii) interpersonal skills training, and (iv) mindfulness. These four components were selected based on the results obtained from the informal carers in the Stage One interviews.

4.5.1 Psychoeducation Interventions

Early interventions focused upon an educational approach that provided information to people in a traditional didactic form to compensate for their lack of knowledge. It was believed that a lack of specific and relevant health knowledge would lead people to engage in behaviours that were not congruent to health benefit (Eisner and Johnson 2008). Psychoeducation was thought to remedy this ignorance by providing participants with information such as diagnostics, symptomology, aetiology and epidemiology of specific illnesses (Newman, Steed and Mulligan 2004). Such information is used to deal with the symptoms displayed by their care receiver and adapt to the life changes that occur as an informal caregiver. It has been recognised that health care professionals could purvey this information to caregivers but are restricted through time restraints and issues with confidentiality (Rowe 2011).

With reference to caregivers for relatives with a mental illness, schizophrenia was the primary condition focused upon and early research recognised that, family education increased caregiver knowledge but the consequences of this were primarily not known (McGill et al. 1983; Barrowclough et al. 1987). Although used as a common structure of interventions, family psychoeducation lacked a definitive role in improving the health of patients until a study by Smith and Birchwood (1987), which reported that, the severity of their care receiver's illness was not effected following family psychoeducation, but rather, that there were improvements in the caregiver's well-being and perceived fear of their relative's behaviours.

These methods of information giving were in adherence with the deficit model by which attitudes and behaviours in relatives were caused by a lack of knowledge, and the information provided would reduce these behaviours associated with lower patient health outcomes. Studies concentrated upon the phenomena of 'expressed emotion' (EE) which refers to emotional over-involvement, hostility and criticism on behalf on the caregiver (Aguilera et al. 2011). Leff and Vaughn (1981) found that caregivers who rated highly for EE were more likely to view their care receiver's behaviour as within their control, and therefore deliberate, whereas the caregivers with low EE were more inclined to recognise behaviours as legitimate manifestations of their illness. Low levels of caregiver EE has been linked to reduced relapse rates in the care receiver, and exploration of the experiences of low EE caregivers of relatives with psychosis revealed that empathy developed through acceptance of the illness and its consequences on their lives (Treanor, Lobban and Barrowclough 2013).

Variations in caregiver attitude and action based on interpretation suggested that the deficit model may not be enough, leading to the creation of the interaction model (Barrowclough and Tarrier 1992). With a greater complexity, the interaction model presented the difference between diseases, the medical and objective pathology, and illness, the subjective effects experience by the patient, and perceived by the caregivers. The authors argued against the deficit model by delineating the egocentric schemas of informal caregivers; rules based around personal experience, that the caregivers implicitly formed that served the basis for their understanding. Therefore, assimilation of new information required for behavioural change, would have to be congruent or familiar with these personally developed models in order to cause change.

Such a model could explain the duality in EE responses found in caregivers by the aforementioned Smith and Birchwood (1987) study whereby those found to have attributed relatives behaviours to the disease rather than them personally, have understood this disparity in congruity with their previously held ideas and beliefs. Further support for the proposal of subjectively established schemata over time is represented in the ease of changing these illness models in caregivers of more recent illness onset than later (Barrowclough et al. 1987), i.e. if personal illness models are derived over time, rigidity and inflexibility to alteration would accrue over time as more experience enforces these beliefs.

Psychoeducational based interventions have been widely utilised in caregiving research especially in areas such as caregivers for those with cancer, dementias, and/or palliative (Fiorillo et al. 2015). Such studies have found that psychoeducation not only increases knowledge of the target disease and it’s symptoms but also improves rates of family functioning (Eldred and Skyes 2008) and caregiver quality of life (Northouse et al. 2012) whilst decreasing rates of anxiety (Katz, Irish and Devins 2004), stress (Visser-Meily et al. 2005) and caregiver burden (Hudson et al. 2012). Whilst these interventions show promising positive effect for psychoeducational interventions, the circumstances under which the experiences of the various subsets of caregivers vary with the implications of their care receiver’s conditions such as disfigurement following surgery, memory loss, palliative care related actions and loss of speech. Interventions for caregivers for relatives with mental health conditions exist also, to a slightly lesser degree, which associate more closely to the experiences of caregivers of relatives with BD.

An early investigation into the functional value of knowledge pertaining to schizophrenia in caregivers of persons with such mental illness was undertaken by Barrowclough et al. (1987). The impetus was placed upon the functional value of the information attained rather than a simple measure of rote recall. Following the information session, the caregivers' knowledge had gone from negatively or neutrally functional to positively functional in six out of seven sections, the latter pertaining to medication was reported as approaching significance. Such a change in knowledge and its functionality clearly displayed the potential for caregivers of those with mental health conditions to achieve positive change from psychoeducational intervention.

More recently, an evaluation of information assimilation was conducted with eighteen relative caregivers including spouses, siblings and children of care receivers with schizophrenia (Caqueo-Urízar, Gutiérrez-Maldonado and Palma-Faúndez 2011). The study found increased caregiver knowledge of the information presented to them; however this particular intervention failed to significantly alter the caregiver's perceptions regarding symptomology and aetiology, which would indicate a lack of personalisation of information in accordance with the interaction model (Barrowclough and Tarrier 1992). The information presented to the caregivers in this study would appear to be reliant upon an approach based on the deficit model whereby information is provided without the intent of personalised assimilation and therefore less effective.

Macleod, Elliot and Brown (2011) reviewed the ways in which nurses could best support caregivers of those with schizophrenia and found that, knowledge provision was beneficial dependent upon delivery and emphasised the importance of coping. The interaction model would suggest that increased knowledge when internalised and applied becomes a form of coping in itself, displaying that knowledge can empower the caregivers to make informed decisions for themselves.

A continued reliance upon a method proven to be less effective displays a necessity for clear understandings of psychoeducation, not just relating to psychosocial outcomes, but also how caregivers view the meaningfulness and usefulness of the information. By further understanding what types of psychoeducation are useful through feasibility studies, refined and robust components can be created to ensure personalised assimilation with the information. With this information being assimilated maximally, interventions can more effectively elicit the positive outcomes and therefore increase the health and wellbeing of the population being targeted.

Psychoeducation interventions for the population of caregivers of persons with BD are the most predominant intervention type. When the particular form of intervention is justified, the authors tend to rely upon the phenomena of EE (Miklowitz and Hooley 1998; Goldstein, Miklowitz and Richards 2002; Fristad, Gavazzi and Mackinaw-Koons 2003; Eisner and Johnson 2008) whereby increased understanding of BD leads to higher levels of acceptance and awareness in regards to the dissociation between their relative's behaviour and the symptoms they display. Whilst the study of EE is important in understanding the overall effects of the caregiving experience, and psychosocial outcomes are more positive when EE is low (Treanor et al. 2013), the phenomena of EE is perhaps too convoluted and reliant upon these associations with health outcomes to directly describe and understand lived experiences.

Without accurate understandings of experience, intervention development is inhibited as the content cannot be targeted effectively in the absence of clear and concise information regarding the intercept population (Ogilvie, Morant and Goodwin 2005). Whilst it should still be recognised that the construct of EE can indicate those at risk from consequences such as higher perceived stress, strain, and increased relapse in care receivers (Eisner and Johnson 2008), a reliance on the measurement of EE is not substantial in understanding the assimilation of information from a psychoeducational component. This is especially true when psychoeducation is delivered in tandem with other components which would lead to the inclusion of confounding effects to levels of EE, and produce a false positive for the psychoeducational component. Other outcomes such as reduced stress, improved social functioning, adoption of healthier coping styles and improved stress management are also noted outcomes from psychoeducational interventions (Schmall 1995; Rea et al 2003; Jönsson et al 2011) which cannot be attributed, at least in full, to EE alone. Therefore, a focus on EE to understand psychoeducation effectiveness, especially in the current context of a feasibility study, would restrict the understanding of such an intervention component.

To emphasise the importance of information provision to caregivers, Berk et al. (2013) recognised that caregivers had restricted access to publicly available and evidence-based information from which to engage with towards the goal of self-care, and highly valued such sources when discovered. When the authors presented such information to caregivers of a relative with BD more than two-thirds reported making use of said information. Other studies of caregivers of relatives with mental health conditions have also highlighted the inadequate resources available to caregivers (Kerr et al. 2006; Drapalski et al. 2008).

Changing the mindsets of the caregivers can alleviate psychosocial consequences for both caregiver and care receiver (Bernhard et al. 2006) and recent research has also shown that BD caregivers' beliefs can be incongruently independent of care receiver mood states (Lobban et al. 2013). Disparity between mood state and perception leads to emotional strain and anxiety for the caregiver and could therefore be relieved, during care receiver euthymic (between manic and/ or depressive mood states) stages at the very least, through increased understanding and of symptoms. As BD has varying and dynamic symptoms, the disparity between actual displayed symptoms and caregivers' perceptions thereof may be greater than in other caring roles which would enhance the need for intervention with this population.

Evidence shows that dealing with challenging behaviours is the most stress inducing aspect of the role (Robinson, Adkinsson and Weinrich 2001). In psychoeducational interventions, an emphasis on the information on suicidal thoughts and what to do in such a situation should be included. Bernhard et al. (2006) included such an approach and specified dealing with suicidal behaviours as a named aspect of a module in their intervention. The authors do not comment as to why this aspect was included, but reported overall significant improvements in caregiver knowledge of BD and use of healthier coping styles.

In previous studies of caregivers, psychoeducation has shown to alleviate psychosocial consequences such as stress and anxiety, improved social functioning, encourage the adoption of healthier coping styles and reduce subjective burden. The inclusion of such a component is justified through both the highlighted need for it as demonstrated from the Stage one qualitative exploration from the interviews with the informal carers, its prevalence, and reported benefits, for caregivers both generally and specifically for BD (Simoneau et al. 1999; Bland and Harrison 2000; Fristad et al. 2003; Madigan et al. 2012).

4.5.2 Psychoeducation Component Description

The psychoeducational component comprised of: an overview of BD which described mood states and elaborated on manic, depressive and euthymic states, the influences of mood and energy and their resulting states, a jargon buster to explain common clinical terms, the aetiological end epidemiological factors of BD, treatments for BD including medications and treatments, health related behaviours for those with BD and a focus on suicidal behaviours with an ethos of behavioural signs and also what to do should someone express suicidal ideations or actions. In regards to exercises, participants were prompted to note the behaviours of their care recipient and identify to which mood state they belonged, and were also asked to make notes under the headings ‘Bipolar Disorder means…’, ‘Bipolar Disorder is caused by…’, Bipolar Disorder can be treated by…’ and ‘As a caregiver, I can…’.

The information in the component description was to provide caregivers with an understandable, verified and trustworthy source from which to understand more about BD. The exercises were designed to elicit a reflective and individual response to invoke internalisation and personalisation in accordance with the interaction model of health information accrual (Ghadirian, Nasiri and Karami 2009).

Several blank lined pages were provided at the end of the component description document for personal notes or reflections of the participants. These were provided at the end of every intervention component document, the use of which were endorsed to aid accurate feedback at the four month follow up.

4.5.3 Cognitive Behavioural Interventions

Interventions focused on the deliverance of cognitive behavioural techniques are secondary in prominence to psychoeducational interventions and in many instances they include other factors such as therapy groups (Aboulafia-Brakha et al. 2014), mindfulness or relaxation techniques (Piet et al. 2010; Mackenzie et al. 2013), or enhancing social skills (Gendron et al. 1996; Fialho et al. 2012). Whilst these additional intervention techniques were justified by positive outcome, the effects of cognitive behavioural interventions on their own are masked by the confounding effects of these. In some cases authors do not even measure for the effects of cognitive behavioural change and rely upon symptomological outcomes that are proven to be affected by other such intervention components included in their studies (Bernhard et al. 2006; Fialho et al. 2012; Mackenzie et al. 2013).

Interventions using cognitive behavioural techniques to enhance caregiver coping abilities were suggested in the early eighties (Levine, Dastoor and Gendron 1983) and were thought to facilitate caregivers in dealing with the stresses of their role. Cognitive behavioural approaches rest upon the conceptualisation of behaviours as the consequence of processing external or internal sources, the processing of which can lead to positive or negative emotional states depending, respectively, on adaptive or maladaptive interpretations of the stimuli (Beck et al. 1976; Beck 1995; Clark et al. 1999; Marquez-Gonzalez et al. 2007). Caregiver's responses to their role are thought to be mediated by factors such as their appraisal of the situation, the strategies they use to cope and personal attributes such as problem solving skills and assertiveness (Gendron et al. 1996).

Various methods have been employed across the studies utilising cognitive behavioural interventions such as: pleasant activity scheduling (Secker and Brown 2014), returning to activities no longer engaged in following the caregiving role (Aboulafia-Brakha et al. 2014), self-governance training (Fialho et al. 2012), and cognitive restructuring (Gendron et al. 1996; Herbert et al. 2003; Losada et al., 2006; Marquez-Gonzalez et al. 2007). The intention of these efforts is to alter the way in which caregivers experience, adapt and react to the roles and challenges of providing care. The caregivers interviewed in Stage One illuminated many consequences of the role, both positive and negative. Utilising the methods of a cognitive behavioural intervention may allow for a greater appreciation for these positive aspects and reduce the negative aspects.

For example, cognitive restructuring has been shown to greatly benefit caregivers whereby they are trained to be aware of their automatic thoughts (Losada et al. 2006; Aboulafia-Brakha 2014), also referred to as dysfunctional thoughts when they are maladaptive. When automatic thoughts are maladaptive, i.e. distorted through our ways of thinking rather than representative of the experienced event in isolation, caregivers are less likely to behave in an adaptive manner (Chang 1999). The ways in which caregivers perceive and choose to deal with the demands of the caregiving role can greatly impact on their psychosocial health (Herbert et al. 2003), and the provision of cognitive restructuring encourages a healthier and adaptive approach (Marquez-Gonzalez et al. 2007). From the Stage One exploratory interviews with the informal carers, a prominent coping style was that of problem solving. The caregivers displayed great efforts to reflect on previous situations and anticipate possible future outcomes of actions. By ensuring that automatic thoughts do not interfere with the caregiver's perceptions, it would be possible to facilitate problem solving based coping as opposed to emotive based attempts which are associated with lower psychological and health outcomes (Losada et al. 2006).

Studies in which cognitive restructuring have featured as a cognitive behavioural method opt for group interventions whereby caregivers attend meetings held by the study investigators or an appointed qualified person. These groups are structured and contain modules that contain one or more sessions looking at how thinking patterns can lead to behavioural consequences. For example, Secker and Brown (2004) had two of seven intervention models focusing on both the identification of negative thoughts and also for challenging maladaptive rules and beliefs. The former had caregivers identify and rate the strength of belief of negative feelings and thoughts. The latter pertained to challenging thoughts and beliefs that were maladaptive and referred to their caregiving role such as "I am a bad carer", or "There is no future.".

If the caregiver was, for example, to possess an automatic thought of "I am no use at anything.", this does not directly apply to caregiving but would clearly impact upon behaviours of the caregiver that are related both directly and indirectly to caregiving. The Secker and Brown study also initially outlines as a study of a cognitive behavioural intervention but includes modules that would belong to psychoeducational and social skills interventions. The benefits of these inclusions would improve the health outcomes of the caregivers as would be expected of such assistance, but the symptomological and caregiver burden outcomes the study rely upon are subject to effect from these modules, providing a false positive in the effectiveness of the cognitive behavioural modules. The authors do, however, recognise this by concluding that the question of the effectiveness of a cognitive behavioural intervention for caregivers still remains unanswered but poses the question as to why they had not tried to.

Another cognitive behavioural technique used in some caregiving intervention studies was the encouragement or scheduling of pleasant activities (Secker and Brown 2004; Marques-Gonzalez et al 2007). Participants were encouraged to actively seek out activities that they enjoyed and even those that they had given up throughout their time as a caregiver. By specifying time for oneself it was thought that the caregiver's could focus more on themselves and positively shift the self-fulfilment versus self-effacement dyad and improve their psychosocial health outcomes through a higher degree of care for the self (Van der Voort et al. 2009).

Cognitive behavioural interventions for caregivers have had mixed success with a proportion of studies not finding significant change following intervention (Gendron et al. 1996; Chang 1999; Wilkins et al. 1999; Herbert et al. 2003). Some of these have reported positive directions of change without significance, suggesting the possibility that further refinement of method could make a significant difference. Considering that the cognitive behavioural components are rarely measured directly, the true effectiveness of these components are masked and that the studies generally rely upon symptomological outcomes, care receiver ill health could cause substantial changes in the care receivers health and wellbeing beyond any improvements made by engaging in an intervention. The majority of studies also rely upon the caregivers of those with dementias and Alzheimer's, the participants of which would face different challenges to those caring for a relative with BD such as age related factors including a focus on mortality or old age and higher levels of personal care (Gildengers et al. 2013).

Bernhard et al. (2006) tested cognitive behavioural interventions techniques along with psychoeducation of caregivers for a person with BD. The focus of the paper is veered to the health outcomes of the care receiver, however, and with no control group, no direct assessment of cognitive behavioural change and reliance upon purely objective measurements, the study is limited in its applicable use. Without a control group, the effects seen in the caregivers could be due to euthymic or remissive mood states. By not measuring cognitive behavioural change, the effects of the psychoeducational components could mask effectiveness.

The authors report significant change in caregiver knowledge but this is what would be expected of the psychoeducational intervention rather than the cognitive behavioural components. Relying upon objective measurements when little to no objective changes occur when dealing with the caregiver alone, it is unsurprising the authors report no change in burden. Had the authors opted for subjective measures, they may have been more likely to notice changes in ways of thinking and feeling, with these as perhaps truer representations of cognitive behavioural change. The necessity for a robust cognitive behavioural intervention for the caregivers of a person with BD is evident. The potential benefits of such an approach could greatly benefit the health and wellbeing of said population, and further understanding into alternative approaches to provide novel methods of assistance that could provide relief from different aspects of the role than psychoeducation alone.

4.5.4 Cognitive Behavioural Component Description

A model of thoughts and behaviours was initially introduced and outlined with examples of scenarios with both irrational and rational beliefs. Unhelpful thinking styles that were delineated were: All or nothing thinking, over-generalising, mental filtering, disqualifying the positive, jumping to conclusions, magnification, emotional reasoning, labelling, personalisation and the use of 'should' and 'must' statements. The thinking styles were delineated to facilitate the detection of faulty thinking which led to the step by step guiding of challenging these thoughts. Further cognitive restructuring was attempted through examples of framing information in thoughts and how to avoid the fuelling of negative thoughts by allowing thoughts to be objective rather than subjective.

The exercises were spread throughout the component description and participants were encouraged to stop in places till exercises such as completing an automatic thought diary that rated the strength and power of belief of the participant's regularly occurring automatic thoughts. A weekly schedule of positive activity was also included to enable the caregivers to take some time for their own needs in a day, even if they could only spare a little time. Example scenarios of automatic thoughts and their repercussions were followed by worked examples of how to challenge these thoughts. Participants were encouraged to practice with thoughts they felt comfortable with, to minimise emotional unease, and later prompted to use the automatic thoughts rated with the strongest belief if they felt ready.

4.5.5 Social Skills Interventions

Social skills can be understood as a multidimensional construct consisting of behaviours and actions that facilitate the engagement in social discourse (Gresham and Elliot 1987; Rose 1997; Rao, Beidel and Murray 2008). Such behaviours include both the verbal and non-verbal aspects of social interaction. Social support, on the other hand, is a related conceptualisation that focuses more on a person's social networks, i.e. social circle size or number of resources available and provided for them (Hogan, Linden and Najarian 2002). Access to increased resources and facilities allows caregivers the opportunity to seek support, assistance and enhance their opportunities to different forms of aide they may not have known about, or be aware that they were entitled to (McNally, Ben-Schlomo and Newman 1999). The mobilisation and maintenance of social support has been found to be facilitated by increased social skills (Robinson 1988; Hansell et al. 1998). For self-care, this is an important realisation as it permits the enhancement of social support via a self-care viable intervention of social skills.

It should be noted that social skills interventions are not highly reported to have been used with caregivers and no study obtained from the literature search had used them for caregivers of a relative with BD. Despite this, social skills interventions have been shown to be effective, albeit with studies from the 1980s and 1990s when greater focus was given to this possible intervention design but has been given slight attention in regards to caregivers in more recent years. Social support training for caregivers includes: the use of assertive behaviours, initiating conversations about caregiving, expressing appreciation, and requesting help (Robinson 1988). An increase in social skills and social support has the potential to assist in improving wellbeing (Lincoln 2000), and dealing with negative aspects of the role (Rose 1997) including some of those reported by the caregivers in Stage One: 'dealing with challenging behaviours', 'loss of identity', 'caregiver concerns and 'disruption to the future'.

The effects of dealing with challenging behaviours can be partially mitigated against through access to social support. For a professional or non-professional to take responsibility for aspects of care provision ranging from assistance with basic functioning through to complete respite care, receiving external aide can reduce both the objective and subjective negative experiences of care provision (Pistrang and Barker 1998; Chakrabarti and Gill 2002; Pakenham et al 2007). Having greater access to resources grants caregivers the foresight of potential ways of dealing with problems through using different forms of assistance they may not have otherwise considered or known of, and perceived situational control has been shown to be a mediator of stress in caregivers (Atienza, Collins and King 2001).

Robinson (1988) looked out with the impacts of interacting with healthcare teams and also found that caregivers reported higher self-esteem and satisfaction with social support, which he argued played a crucial role in the resulting subjective burden of caregivers. The by-products of increased social skills would then appear to allow the caregivers to develop the social means to engage in healthy and, or, therapeutic relationships that can instil protective factors against perceived burden. This concept is referred to as the social support community framework (House, Landis and Umberson 1988) which highlights the need for seeking and maintaining social support to lower levels of caregiver depression and social isolation (Bass, Noelker and Rechlin 1996).

Caregivers have shown greater acceptance of external assistance with higher self-reported ratings of usefulness when the roles and duties of healthcare workers were outlined and understood (Robinson 1988). It is therefore important to give caregivers the opportunity to know where, who, and how support can be provided with accurate information pertaining to healthcare worker roles and duties to negate misunderstandings and misattribution of expectations. Collaboration between caregivers and healthcare professionals has been shown to not just be beneficial for the psychosocial outcomes of caregivers but also the care receivers (Peternelj-Taylor and Hartley 1993) which amplifies its importance for those concerned.

A key aspect of incongruence between mental health caregivers and healthcare workers has been highlighted by both sides as patient confidentiality and how this relates to the caregiver (Wynaden and Orb 2005; Maskill et al. 2010). Caregivers can negotiate with their care receiver to be given access to information of their hospital based care, but in some cases care receivers may not want to share this information, or healthcare workers may feel this would be detrimental to the planned care.

Those who identify as caregivers are more likely to seek social support as they recognise the role they play as distinct from a familial obligation (Talley and Montgomery 2013). Carer identity and social support are evidently interconnected, with identity encouraging external support seeking, and support facilitating the development of identity. In relation to self-care, the relationship of identity leading to social support should be focused upon to best utilise this interconnection.

4.5.6 Social Skills Component Description

An introduction in how people communicate outlined the many different ways we can and do express ourselves. Participants are asked to reflect on times when they felt listened to and not listened to, and consider what was different that led them to feel this way. Verbal communication was defined and focused on word use: both for choosing our words congruently with our feelings, and to detect particular word choices in those we are listening to, reflective listening: the process whereby a speaker shows they were listening and feeds this back in their response and other aspects of speech: volume, tone and the use of silence. Non-verbal communication followed on after some examples and practice exercises for reflective feedback examples provided. Non-verbal communication described body language, the role of eyes in emotion portrayal, and non-verbal ways of communicating listening.

The latter half of the component outlined healthcare professionals and the roles and capacities that they would most likely encounter them and outlined advocacy rights and resources for caregivers. The Carer's Assessment was also described and information on accessing an assessment including a draft letter to achieve this was included. The component description ended with the potential financial assistance and benefits for caregivers and care receivers. This included an explanation of the change from Disability Living Allowance to Personal Independence Payment (https://www.gov.uk/pip/overview) that was being progressively implemented across the United Kingdom before and after the intervention was piloted.

4.5.7 Mindfulness Interventions

The fourth and final intervention component utilised the approach of mindfulness. Mindfulness refers to a state of introspective attention and awareness of affective states, physical sensations, perceptions and thoughts in an observational and non-judgemental way (Grossman et al. 2004; Fledderus et al. 2010; Cullen 2011). The aim of mindfulness is to allow the non-conscious aspects of cognitive experience to be attended to in order to recognise and accept the presence of, not to be mistaken with accepting the validity of the construct. All mental constructs are to be acknowledged non-judgementally through the refinement of shifting ones attention, allowing the experience of the current moment (Piet 2010; Glük and Maercker 2011). The origins of this method stem from early Buddhist tradition in which existence itself is the experience of suffering and a state of mindfulness facilitates the avoidance of this. From a clinical perspective, the impetus of mindfulness is linked to psychosocial and symptomological outcomes as these can be measured accurately, unlike the meditative religious practices from which they stem (Baer and Saur 2009; Harrington and Pickels 2009).

Interventions using mindfulness techniques have reported numerous beneficial outcomes such as an increase perceived control, wellbeing, life satisfaction, emotional regulation and reduction in depression, stress, absent mindedness, and fatigue (Brown and Ryan, 2003; Carmody and Baer 2007; Grossman et al. 2010; Deckersbach et al. 2011). Several variations of mindfulness have developed in the form of mindfulness-based stress reduction (MBSR: Kabat-Zinn 1982), dialectical behaviour therapy (DBT: Linehan 1993), acceptance and commitment therapy (ACT: Hayes, Strosahl and Wilson 1999) and mindfulness-based cognitive therapy (MBCT: Segal, Williams and Teasdale 2002). These approaches have been markedly variable in design and extent to which basic mindfulness techniques are utilised (Baer, Walsh and Lykins, 2009).

MBSR can be considered to be the original mindfulness intervention, instigated by Kabat-Zinn (1982) of whom the mindfulness movement in health research is attributed. This type of intervention intends to develop mindful awareness and relies upon the assumption that individuals are largely unaware of their continual experiences that this skill can be taught and also develops with practice (Grossman et al 2004). The formal practices of mindfulness interventions include: the body scan, breathing exercises, mindful movement and meditation. The exercises focus on the cultivation of awareness and the ability to both harness and direct it in the effort of becoming mindful and fully experiencing the present moment (Cullen 2011). The increased accrual and awareness of experience enables effective and adaptive behavioural responses, i.e. healthier methods of coping styles, and a resultant increase in perceived control (Kabat-Zinn 1990; Bucheld, Grossman and Walach 2002).

In 2009, a review of empirical studies of MBSR interventions by Irving, Dobkin and Park was undertaken in healthcare professionals and found that the consequences of their occupations in caring for others brought increased stress and burnout which lead to impaired quality of care provision. Engaging in mindfulness techniques improved both the physical and mental health of the healthcare workers and observed a return in the levels of quality of care provision. Considering that informal caregivers provide similar, if not greater, levels of care than their professional counterparts, it would not be amiss to believe that the effects of caring for a relative could be mediated by mindfulness practice (Shapiro, Brown and Biegel 2007). Research pertaining to mindfulness intervention with relative caregivers is majoritively based on those caring for relatives with dementias or Alzheimer's disease.

Caregiver mindfulness interventions are uncommon and several studies use questionable methodologies such like Innes et al. (2012) who aimed to assess a mindfulness intervention on persons with Alzheimer's disease and their caregivers. The authors evaluated the impact of an 8-week mindfulness intervention on stress, sleep, and mood which would lead to novel insights; however, the authors included only ten participants in their study. Only two of these participants are caregivers, and the low numbers did not allow for distinction between those providing and receiving care, therefore confounding the effects of the intervention.

From the literature evidence reviewed the evidence shows that no study obtained from the literature search assessed the effect of a mindfulness intervention on the caregivers of persons with BD, so little is known whether such an approach would be effective or meaningful. Although, we can gain a prospective assertion from the literature focused on caregivers of older adults with dementia. MBSR has been shown to be more effective than community caregiver education and support which consisted of a social group and emotional support in improving mental health and reducing stress (Robins et al. 2013). Improved outcomes from a mindfulness based approach compared to an educational approach suggests that mindfulness interventions have a place in providing support to caregivers that may not be provided by the prototypal psychoeducational approach.

Many studies with caregivers have reported quantitatively and qualitatively, the increased use of mindfulness techniques following mindfulness interventions resulting in decreased stress, depression, psychological discomfort and improved cognitive and emotional function, peace and hope (Waelde, Thompson and Gallagher-Thompson 2004; Franco, Sola and Justo 2010; Epstein-Lubow et al. 2011; Hoppes et al. 2012; Lavretsky et al. 2013). However, several studies report limited success with a mindfulness intervention (Oken et al. 2010) and in one instance, no accrual of mindfulness practice at all (Glük and Maercker 2011) but this particular study recognised its own possible limitations through participant selection bias. Overall, for the caregivers from mindfulness intervention research, mindfulness is beneficial not only for alleviating negative consequences of the role but also facilitating the positive aspects.

A mindfulness component in this study could produce the same benefits such as improved wellbeing and reduced psychiatric symptoms as is found in those of caregivers for older adults with dementias. The situations between the caregivers may not overlap through varying symptoms from care receivers (Chakrabarti and Gill 2002; Bernhard et al. 2006). The catch of 'Being Bound' and experiencing negative effect from being away from their care receiver greatly impacts upon caregivers of relatives with BD, as was reported in Stage One of the study. The alleviation of this problem would allow caregivers to take more time for themselves and could enhance self-esteem, stress and coping styles.

4.5.8 Mindfulness Component Description

The mindfulness component was the final quarter of the intervention booklet. It began with an introduction into how our thoughts can take us from the present to both the past and the future, and how these can influence our thoughts and feelings, i.e. feelings of depression and anxiety. The benefits of being able to focus on the 'Here and now' was outlined and what the present moment is as how we can both ignore and notice it along with the benefits of clarity, awareness, and unhindered critical thinking. An explanation of how and why we tend not to be mindful was also added to emphasise that people generally err on the less mindful unless prompted or trained (Baer et al. 2006).

The posture and setting for allowing mindfulness was explained and alternatives were given for those who would find the posture uncomfortable. The first exercise encouraged the control of attention using the task of breathing. Participants were prompted to focus on the experience of breathing to exemplify the taken-for-granted experiences of every day. This task was suggested to last five to ten minutes each day for a week and participants were asked to describe in their own words their experiences. The next exercise moved on from the control of attention to its direction and shifting, whereby a body scan was undertaken.

The body scan built upon the skills of exercise one whereby participants shifted their attention to different parts of their body and relaxed them synchronously with their breathing. Any thoughts that intruded this practice were to be attended to by noticing them and then letting them go, without judging the nature of the thought. This task also lasted a week and those who felt efficient in the task were instructed to further break down body scan areas into smaller constituent parts. Scores were asked to be recorded from 0 (lowest) – 10 (Highest) representing ‘Feeling in the moment’ and ‘Ease of controlling distractions and focusing.’ to chart progress.

Exercise three involved using mindfulness with negative emotions and encouraged the process of attending to intruding thoughts and feelings and to use mindfulness to explore them and acknowledge them. Only thoughts and feelings that participants felt safe exploring were suggested to avoid unnecessary emotional responses from strong feelings. The aim of exercise three was not to alter these emotions but to be mindful of them. The component description ended with a guide of when to be mindful and how to gain the space to do so.

4.6 Use of Stage One Qualitative Findings to Inform Intervention Components

Within the theme of Caregiver Knowledge of Bipolar Disorder that emerged from analysis of the exploratory qualitative interview data collected participants reported difficulty in sourcing and validating information pertaining to the BD. Provision of psychoeducational material would deliver such a source of information that the caregivers refer to in confidence (Berk et al. 2013). Also, in line with the interaction model, some of the caregivers displayed an appreciation for the dissociation between their care receiver and their illness, and all caregivers framing their understanding of BD on their own personal experiences.

The information delivered via psychoeducational intervention is a recognised need by the caregivers and their developed understandings of BD through subjective experience. This indicates the necessity to follow the interaction model of information provision so that schemata can be altered through internalisation and personalisation of the new information provided (Macleod, Elliot and Brown 2011). Such a process would not only provide information but change the perceptions of the caregivers in regards to their beliefs about illness related behaviours.

The informal caregivers interviewed expressed the greatest personal incomprehension of suicidal ideations:
"*When things were worse and she would talk about suicide and that, I found that hard. I hadn't a clue what to say to someone like that, I'd never heard someone be so abrupt about such a thing*." – Quote from participant in Stage One Interview.

Although communication was recognised by them as a useful coping strategy, they found it difficult to discuss such behaviours and found dealing with them burdensome and detrimental to their own wellbeing.

Psychoeducational intervention was recognised as a need by the participants as reported in Stage One through their interviews of the lack of availability and reliability of resources, which concurs with evidence in other studies exploring the caregiving experience (Berk et al 2013). The way in which the informal caregivers appeared to have made sense of BD was in relation to personal experience, and displays the need for information provision in accordance with the interaction model.

The effects of psychoeducation on caregiver perception of care recipient behaviours, increased awareness, and the capacity to make informed decisions would facilitate the large number of care provisions that the informal caregivers in this study reported. Having to not only provide personal care such as cooking and cleaning for their relative, they were expected to provide emotional support and also encourage treatment adherence.

The ability to fulfil these roles would be made easier through increased perception of symptoms, an understanding of treatments regarding BD behaviours to the condition, rather than the person recipient of their care. Such increased awareness of the BD and related challenges may also lead to increased empathy for their care receiver, and ease the transition of identifying as a caregiver, the realisation and acceptance of such is known to be associated with more positive health outcomes (Bland and Harrison 2000).

The prevalence of caregiving concerns from the Stage One interviews with the informal carers highlighted how their worries and anxieties stemmed from ruminations of possibilities which had negatively influenced their psychosocial health. Alleviation of maladaptive thinking concerning these aspects would decrease the frequency and intensity of such concerns (Losada et al. 2006). Not only would the facilitation of awareness and consequential challenging of automatic thoughts assist in the reduction of maladaptive coping and behaviours, it may also allow the caregivers to appreciate the positive aspects of caring. Through challenging negative automatic thoughts, it may be possible for the caregivers to then perceive the beneficial aspects of their roles that the informal caregivers in the Stage One interviews reported.

As the caregivers gained experience of the role, their clarity of the situation improved with their abilities and adaption to the role. Aiding the realisation of positive aspects could also improve the health outcomes of the caregivers, and allow them to overcome the reported loss of identity by supporting their identity formation of caregiver (Lawton et al. 1989; Hunt 2003; Brouwer et al. 2005; Langeland et al. 2007).

The caregivers also reported a lack of identity which coincided with feeling unsupported in their role. The lack of definition and understanding in who and what they were supposed to be and do, had resulted in confusion and an inability to understandably define oneself. They also struggled with the concept of confidentiality and how it was used. Studies have suggested that increased social support can allow caregivers to plan and understand their care duties, based around their care receivers needs and facilitate the progression to identifying as a caregiver (Talley and Montgomery 2013). This sense of identity can increase the caregivers self-esteem, coping styles and tendency for self-fulfilment which can otherwise be overtly in the favour of self-sacrifice in the provision of care to their relative (Chakrabarti and Gill 2002; Shapiro, Brown and Biegel 2007; Jönsson et al. 2011).

The informal carers in Stage One of the study expressed concerns primarily around what would happen to their care receiver if they were to no longer be able to provide care. Increased social support would allow caregivers greater opportunity to explore the potential external assistance that could help in such an instance. Disruption to the future can similarly be attended to in such a way but rather than undoing the changes which could potentially be unyielding, increased social support could help realistically shape the future for the caregivers. The coping method of acceptance allowed the caregivers to realise that their future was changed and external support could allow for the reformation of a secure and helpful prospects for both caregiver and care receiver. Factors that can affect this acceptance include locus of control, perceived identity of caregiver and social support (Rose, Mallinson and Walton-Moss 2002; Champlin 2009). Social support is evidently beneficial for these three components and further indicates the necessity of the exploration of the benefits of social skill based interventions in the context of the study

Such skills in coping are pertinent to those providing care, and the coping styles of the informal carers in Stage One were numerous, and the encouraged development of these would provide protective means to the negative outcomes of the role. The initial impetus of the mindfulness component, however, arose from the caregivers' dilemma of 'Being Bound' to their care receiver whilst experiencing negative emotional responses such as guilt, anxiety and worry when separated from them. Mindfulness may provide caregivers with the space they feel they require to not feel 'bound' whilst allowing them to be in close enough contact as not to elicit negative effect. The appreciation of the present moment provides a sense of experience and awareness that can instil a greater appreciation of the 'here and now', even during routine tasks (de Vibe 2012), so time spent mindful may even be experienced as a greater period of personal time, than a comparative activity without the engagement of mindfulness.

A summary of how each component was informed by the informal carers lived experiences explored in Stage One of the study is presented in Table 1.

Table 1. A summary table representing the aspects of lived experiences that informed each component.

Component Informed	Summary of lived experiences used
Psychoeducation	• Reported lack of information sources and ability to verify these. • Relatives' behaviours were perceived through own subjective perceptions. • Distress caused by incomprehension of suicidal ideations. • Expectations to assist in treatment adherence. • Lack of knowledge regarding treatments.
Cognitive Behavioural	• Positive aspects showing potential areas to recognise. • Constant ruminations regarding relative's health even when euthymic. • Loss of identity and indecision around seeing oneself as a care giver. • Focus on possible future outcomes caused concern. • Unsure as to how to proceed with their care provision. • Wide array of coping styles reported.
Social Skills	• Confusion or misinterpretation of healthcare worker roles. • Ambiguous carer identity. • Uncertainty around the future for themselves and their relative.
Mindfulness	• The dilemma of being bound to their relative but also wanting their own space. • Need for adaptive responses to relatives' behaviours and care provision.

4.7 Further Intervention Development Considerations

Each intervention began with a foreword from the primary researcher for the study. The foreword reiterated the instructions from the information sheet provided to participants for clarity. Furthermore, the terms caregiver and care receiver were explained to prompt them to focus on their role and experiences, and did not imply that their relative did not provide support to them in other ways, to avoid confusion. Participants were informed that their booklets were their own to keep and would not have to be returned, an approach adopted to encourage a congruent, honest exercise completion and note taking throughout the implementation timeframe.

Additionally, quotes from the informal carers experiences explored during the interviews in Stage One were included at the base of some pages, the rationale for this is to provide real lived experiences that closely related to what that page and component meant. This was an effort to overcome a limitation of self-care whereby all work is done alone. The quotes were included in light of the resulting theme of 'Peer Support' in the 'Caregiver Coping styles' from the Stage One interviews.

4.8 Issues in previous caregiver intervention evaluation

Several impediments regarding caregiver intervention evaluation have been highlighted, including: the use of non-validated assessment tools, a reliance on single and concomitant measurements, and use of generalised scales (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002; Ogilvie, Morant and Goodwin 2005; Reinares et al. 2006; Goossens et al. 2008). Considering that intervention research focused specifically upon the population of informal caregivers for relatives of those with BD are limited, the inclusion of these critiqued aspects from the reviewed literature reduces the reliability, and therefore utility, of information gained to produce robust and effective interventions.

Many studies have included caregivers in family involved interventions but tend to have a higher emphasis on patient outcome and rarely evaluate caregiver outcomes using primary measures (Perlick et al. 2007; Reinares et al. 2008). Such a considering of caregivers as an adjunctive to treatment and adherence do not provide sufficient information regarding caregiver responses to intervention assistance. An ethos for the improvement in health of patients living at home is reasonable, but considering that results from caregiver interventions are mixed, and in some cases methodologically invalid and flawed, caregiver health and wellbeing should be considered independently. By using patient outcomes such as mood state and relapse occurrence (Reinares et al. 2008) as a measurement of caregiver intervention, many confounding factors including care receiver health, treatment adherence, and coping styles could all impact on such measures. Therefore, efforts should be made to focus on caregiver outcomes that directly relate to the intervention assistance provided in a study. However, many caregiving studies that do focus solely upon caregiver outcomes continue to rely upon the phenomena of burden in evaluation.

The term burden is generally considered to involve the emotional, physical, financial and/or psychological consequences of engaging in care-related tasks and behaviours (Poulshock and Deimling 1984; Kosberg, Cairl and Keller 1990; Deekan et al. 2003). Considered to be an 'umbrella' term that encapsulates the consequences of informal care provision rather than describing it, the term burden lacks conceptualisation despite attempts at doing so (Houlihan 1987; Chenier 1997; Chou 2000).

With reference to intervention studies, burden as a component of evaluation is both restrictive and vague. Without a concrete definition, measures of burden can be associated to various health and wellbeing outcomes with only a propensity of causality. The very nature of attempts at understanding caregiver burden have been made by comparisons with non-caregivers, and it has been argued that burden itself is not relevant to non-caregivers, and that burden may be over-reported in those providing care as they associate the two so closely (George and Gwyther 1986; Stull, Kosloski and Kercher 1994). It may be this understanding of burden that has limited conceptualisation and also limits the validity of burden comparison between those providing care and those who do not. The term burden still endures as a prominent measure in caregiving research despite these limitations, and many studies opt for measuring both the subjective and objective aspects of burden, with the hope to alleviate these through self-care and practitioner led interventions (Jones 1996; Lam et al. 2005; Maji et al. 2011).

The inclusion of objective measurement is somewhat restricted by the nature of the interventions, as they tend to influence subjective factors such as coping styles and caregiver knowledge rather than the objective aspects of care, i.e. the actual tasks involved. Many intervention studies fail to recognise that the dichotomy of burden measures are limited in their use, and despite not influencing the objective aspects of the role, include both burden measures or even global measures of burden which would have inseparable subjective and objective components which would mask intervention effectiveness (Baldassano 2004; Bernhard et al. 2006; Maji et al. 2011)

If the ways in which to enhance the health and wellbeing of those providing informal care is to be achieved, reliance upon general or global assessments should be avoided in favour of targeted measures that accurately assess the engagement and assimilation of intervention assistance (Ogilvie, Morant and Goodwin 2005; Reinares et al. 2006; Goossens et al. 2008). Unidimensional assessment is inadequate to comprehend the multifaceted outcomes of the caregiving role, especially when interventions are multi-component, i.e. complex. If measurements are not direct, then assimilation of intended information is unknown and results may instead relate to involvement with the intervention rather than engaged intervention effectiveness.

The importance of understanding wellbeing and not just an absence of ill-health as a standard for intervention assistance is reflected in the work of Nolan et al. (2004) where the very concept of 'person-centred' care is questioned at an existential level of being. The authors refer instead to consider personhood, the consideration of what it is to be a person. This aligns closely with Gadamer's views of existence through the appreciation of our interpretations of our environments, our *lifeworlds*, rather than objectively in response to them (Marino 2012). Following the same argument, single component interventions must be justified in their absence of other approaches that could influence positive health outcomes (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002). The experiences of the caregivers should be appreciated to be wide reaching and require complex interventions to meet this need.

Bernhard et al. (2006) tested such a complex intervention that included both psychoeducational and cognitive behavioural components for those caring for relatives with BD. The authors measured expressed emotion (EE), burden, and depression with no direct measurement of change in caregiver knowledge or cognitive behavioural outcomes. Arguably, the expressed emotion and depression measurement are perhaps more related to psychoeducation and cognitive behavioural interventions consecutively, but there is no control for influence from either component on any of these outcomes. For example, if the psychoeducational component were to be beneficial in increasing caregiver knowledge, this would have to be expressed indirectly through a change in expressed emotion (EE), a distinct and separate phenomenon, and withstand any influence on attitude and thoughts that may be elicited by the cognitive behavioural component.

Such measurement of a multi-component intervention is illustrative of the faults in evaluation in caregiver research. Considering that the effectiveness of caregiver interventions have been questioned to date, it is imperative that attempts to evaluate interventions should be as robust and validated as the intervention itself in order to ensure that information that relates to helping the caregiving population can be effectively produced and utilised. Other interventions for caregivers of persons with BD show similar limitations in evaluation that could influence measured effectiveness. These include the non-validated adaption of caregiver knowledge questionnaires for other conditions (Madigan et al. 2012), failing to include measurements pertaining to the actual intervention type and relying upon secondary or symptomological measures (van Gent and Zwart 1991; Kim and Miklowitz 2004; Bernhard et al. 2006; Simoneau et al. 2009; Perlick et al. 2010), measures designed for populations of caregivers of older adults (Jönsson et al. 2011).

These evaluation issues must be attended to, corrected and avoided in order to produce effectiveness data for caregiver interventions that are reliable. As caregiver interventions are recommended to be complex (Knight, Lutzky and Macofsky-Urban 1993; Ogilvie, Morant and Goodwin 2005), consideration for assimilation assessment should be made to determine to which extent the components are interacted with in intervention research.

Symptomological and global measures, whilst informative in their own right, do not provide targeted information regarding intervention effectiveness, as they are subject to confounding variables which may over and underestimate intervention effectiveness. Assessment tools that are used should also be validated to best represent changes in health and wellbeing to enhance the understanding of what can benefit those caring for a person with BD (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002; Ogilvie, Morant and Goodwin 2005; Reinares et al. 2006; Goossens et al. 2008). As such an intervention in itself is novel, and therefore it would require to be piloted so that lessons can be learned

4.9 The importance of Feasibility Evaluation

The updated guidance for the development and evaluation of complex intervention from the Medical Research Council (MRC) emphasises the importance of pilot studies to provide feasibility information (Craig et al. 2008). Factors such as acceptability, compliance, retention and delivery are highlighted as crucial aspects to evaluate. This feasibility aspect is what enhances a pilot study beyond a scaled-down version of a larger study to the purpose of providing insight in to positive effect of interventions, along with the information required to further enhance and refine such intervention attempts (Patel, Doku and Tennakoon 2003; Arain et al. 2010).

The current study aim was to provide such information and as such, will explore the effects, or lack thereof, of the developed intervention components, but provide information regarding recruitment, retention of participants, procedures and feedback from participants regarding their perceptions, acceptance and opinions of the study. Obtaining such feasibility information facilitates the further enhancement of a multi-component intervention to enhance the health and wellbeing of those who care for a relative with BD.

Within Chapter 4, the content of the multi-component intervention piloted in Stage Three of this study is described for increased transparency regarding the process and actual tested materials as previous caregiver intervention research has been critiqued for being vague, general or just lacking in information of interventions tested (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Habil and Duberstein 2002). Information derived from a pilot study is of greater importance when dealing with complex or multi-component interventions for caregivers to ensure that effects are clearly and concisely measured (Ogilvie, Morant and Goodwin 2005; Arain et al. 2010).

4.10 Evaluation of the Four Pilot Intervention Components

To meet the methodological criteria outlined by previous studies (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002; Ogilvie, Morant and Goodwin 2005; Reinares et al. 2006; Goossens et al. 2008) the outcome measures had to be selected carefully. Due to the nature of a multi-component intervention, several components could cause supporting or even countering effects on the same outcome. As an example, if component A created an increase in outcome Z and component B created a negative in outcome Z, the effects of both components would be lost. For this reason, each component had to be measured in its own right, with the change viewed in this outcome to be attributable to itself alone. The four intervention components were assessed by a single outcome measure, except for the cognitive behavioural component which used two, to represent the extent to which the participants had interacted with said component.

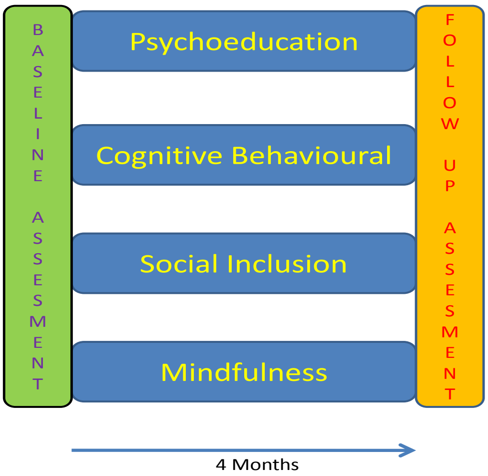


Figure 1: Representation of the longitudinal pilot evaluation of the multicomponent intervention.

As stated, evaluation of the intervention being piloted would have to account for the four separate components that it contains. Each of the four intervention types would have to be assessed to gauge the extent to which participants had interacted with and assimilated the information they provide. Such assessment tools would have to be validated primary measures of the intended effect of each component, rather than secondary or symptomological factors. The measurement for each component is outlined and justified below.

4.10.1 Evaluation of the psychoeducational component

The Understanding Mood Disorders Questionnaire (UMQD: Gavazzi, Fristad and Law 1997) consists of twenty questions ascertaining to the knowledge of symptoms, treatment and course of mood disorder, and a nineteen item checklist assessing the awareness of manic and depressive symptoms. The two subscales combine for a total score of fifty nine as the initial twenty questions are double weighted compared to the symptom checklists. Increased score relates to increased knowledge of mood disorders and acknowledgement of symptoms. The UMDQ has shown good internal consistency (ɑ = .73) in an early psychometric study (Gavazzi, Fristad and Law 1997) and more recently with caregivers of relatives with BD (ɑ = .81) (Eisner and Johnson 2008).

Most recently, the UMDQ has been used in the assessment of a multi-family psychoeducation psychotherapy in conjunction with clinician reporting of more accurate knowledge and better understanding of mood disorders (MacPherson, Leffler and Fristad 2014). Both the UMDW and clinician reports showed significant improvement following the intervention. The UMDQ has also been shown to be positively correlated with the Treatment Beliefs Questionnaire (TBQ) with a population of caregivers (Davidson and Fristad 2006).

Several studies have used the UMDQ to assess change in knowledge of mood disorder, treatment and course of illness in caregivers (Fristad, Arnett and Mitzi 1998; Fristad, Goldberg-Arnold and Gavazzi 2002; Davidson and Fristad 2006). A potential limitation of the UMDQ is that it refers to mood disorders in general and has been used, for example, in studies for caregivers of persons with schizo-affective disorder (Klaus et al. 2008) which may suggest that the questionnaire may not be targeted enough. However, the subscales possessed by the UMDQ refer to responses to both facts and symptoms. The symptoms are those of mania and depressive symptoms, so the UMDQ is arguably a better fit for populations with BD rather than depression only. Change in knowledge has been observed to be reflected by the UMDQ following psychoeducational interventions and while other disorder knowledge assessment tools may have been used in other studies (Madigan et al. 2012), adapted versions that are modified to suit a BD population are not validated and may mask effectiveness (Ogilvie, Morant and Goodwin 2005).

4.10.2 Evaluation of the cognitive behavioural component

The Automatic Thoughts Questionnaire (ATQ: Hollon and Kendall 1980) and the Positive Automatic Thoughts Questionnaire (ATQ-P: Ingram and Wisnicki 1988) were chosen to evaluate the cognitive behavioural component. As was discussed in Chapter 6, both negative and positive aspects of the caregiving role were found, and as these would be most evident in measures of cognition, both a negative and positive assessment were selected to measure the dichotomous nature of thoughts regarding caregiving.

The ATQ consists of thirty items, each of which represent a negative self-statement, the frequency of which the participant experiences each thought is noted using a five point Likert scale ranging from not at all to all the time. It has displayed high internal consistency and correlates positively with assessments of anxiety, depression, external locus of control and hopelessness (Kazdin 1990; Hollon 2002). Increased scores denote increased reported negative automatic thoughts.

The assessment of the presence of automatic thoughts is restricted to a degree as the presence or absence of certain thoughts may not fully depict the influence of a cognitive behavioural approach. Nonetheless, many cognitive behavioural interventions for caregivers have relied on symptomological outcomes to determine cognitive behavioural change (Bernhard et al. 2006; Perlick 2010; Mackenzie 2013; Aboulafia-Brakha et al. 2014). Symptomological outcomes are not insusceptible to other factors, i.e. are not dependent solely upon cognitive behavioural change elicited by an intervention, and therefore inaccurate measures. Additonally, research papers report the inclusion of social skills training (Fialho et al. 2012) and relaxation training akin to aspects of mindfulness (Secker and Brown 2014), as part of their cognitive behavioural interventions without regard for distinct measurement of these individual approaches.

As the current developed intervention in this study includes four distinct components, efforts must be made to ensure that evaluations of each component are as accurate as possible, further necessitating direct and primary assessment. Finding a validated assessment tool to assess the change in cognitive behavioural intervention proved difficult due to the lack of studies that utilised such evaluation and consideration to the cognitive restructuring ethos of the cognitive behavioural model in this study's intervention, automatic thoughts were determined unique to this particular component (Joseph 1994).

Considerations were made towards the mindfulness component and how the nature of mindfulness also ascertains to thoughts. However, mindfulness is not designed to directly alter the quantity or nature of automatic thoughts but to accept their presence (Baer, Walsh and Lykins et al. 2009; Cash and Whittingham 2010). The mindfulness intervention may, for this reason, be counterproductive towards the measurement of automatic thoughts as participants may become more aware of these, as they progress through the intervention and eliminate any benefit in negative automatic thought reduction. While the possibility of this stands, little evidence suggests this effect is recognised (McConachie et al. 2014).

Gendron et al. (1996) used the ATQ to assess a cognitive-behavioural intervention for spousal caregivers of those with dementia. Cognitive restructuring played an integral aspect of their intervention and was led by a trained professional. Eighteen caregivers were tested pre- and post-intervention but a significant difference in ATQ scores did not reach significance (*p* = .06) but was close. Considering the small population tested, the study could provide a positive indication to a larger scale study and shows that the ATQ is at least sensitive to cognitive behavioural change in caregivers.

The ATQ-P supplements and shares the same format as the ATQ with thirty statements rated one to five for frequency of occurrence but the statements refer to positive self-statements. The ATQ has good construct validity and is able to differentiate between depressed and non-depressed respondents and correlating inversely with negative health outcomes (Ingram and Wisnicki 1988; Lightsey 1994; Ingram et al. 1995; Boelen and Van Den Bout 2002). The ATQ-P has not been used in caregivers of relatives with BD, but the inclusion of this measure would ensure a whole state evaluation (illness and wellness) of automatic thoughts rather than being limited to negatives thoughts only.

The ATQ-P has recently been used to measure positive thinking in relation to cognitive modification (Clore and Gaynor 2010), wellbeing (Wong 2010), and positive affect (Lightsey et al. 2012) in healthy populations following cognitive behavioural intervention, and with patients with depression following group cognitive behavioural therapy (Forsyth et al. 2010); which evidences the tool's propensity and sensitivity to change for this type of intervention. Increased score reflects an increased number of reported positive automatic thoughts.

4.10.3 Evaluation of the social skills component

The Social Support Questionnaire-6 (SSQ-6: Sarason et al. 1987) was chosen to evaluate participant involvement with the social skills component of the intervention. The SSQ-6 is the abbreviated version of the 27-item Social Support Questionnaire (SSQ: Sarason et al 1983) and the abbreviated form was selected as "the SSQ6 [SSQ-B] is psychometrically sound, and when time of administration is a consideration, the SSQ6 is an acceptable substitute for the SSQ." (Sarason et al. 1987, pg. 506). Due to the number of assessment tools selected for use, a shorter yet still effective alternative would allow for results at a reduced cost of time for those taking part.

The SSQ-6 presents six social scenarios and asks participants to rate both objectively, the number of people they can rely upon in that situation, and subjectively, how satisfied with the help they perceive they have. As social support is a product of enhanced social skills (Bodell et al. 2011; Cheng et al. 2013), the purpose of the social skills intervention is to enhance the caregivers ability to gain and maintain supportive relationships and the SSQ-6 provides both the objective and subjective changes, which are beneficial for the pilot study as it is unknown if one or both of these facets will increase with the intervention. Increased scores denote greater objective support, i.e. persons who could help, and subjective satisfaction, i.e. the extent to which this support is deemed adequate.

With regards to content validity, the SSQ-6 was derived from the SSQ using factor analysis to identify the six items that had the highest factor loadings. Both subscales are reliable with Cronbach's alpha ranging from .9 to .93 (Sarason et al. 1987) and shows significant correlations with anxiety and depression measures. Pakenham et al (2007) studied young carers and found that higher levels of social support from both subscales significantly reduced caregiver distress. This relationship with distress was also found in mothers of those caring for children with chronic physical illness (Horton and Wallander 2001). The SSQ-6 has also recently been used in the evaluation of depression (Gay et al. 2010), quality of life (Cheng et al. 2013), and negative life events (Bodell et al. 2011).

Due to the self-care nature of the intervention, the social skills component it was hoped would elicit changes in social behaviours, and allowing caregivers to engage in more socially supportive relationships. The benefit of the SSQ-6 to this is the independent scores for both objective and perceived happiness with social support. Consideration for both the observable and the appreciated re-iterates the stance of Nolan et al. (2004) to appreciate caregivers in their own right.

4.10.4 Evaluation of the mindfulness component

The Five Facet Mindfulness Questionnaire (FFMQ: Baer et al. 2006) was selected to measure participant involvement with the mindfulness component. The FFMQ consists of thirty-nine items and five subscales that comprise the five factors that represent mindfulness based on a factor analytic study: observing, describing, acting with awareness, non-judgement of inner experience, and non-reactivity to inner experience. Each item is scored on a five point Likert scale to denote agreement with the statement ranging from 'never or rarely true' to very often or always true'. Higher scores in each subscale refer to increased aspects of mindfulness.

The FFMQ is able to measure changes in mindfulness even in populations that have little or no meditation experience (Baer et al. 2006), which is beneficial as experience in thefield with caregivers is unknown, and the questionnaire has been reported to have good internal consistency (de Bruin et al. 2012). It has been used in studies investigating the effects of wellbeing following stress reduction intervention, and to measure changes in mindfulness in studies investigating post-traumatic stress disorder (Thompson and Waltz 2010), wellbeing and depressive and anxious symptomology (Cash and Whittingham 2010), emotional distress (Kiken and Shook 2012) and psychological control (Bowlin and Baer 2012).

Within the caregiving population, the FFMQ has measured mindfulness following mindfulness based interventions to reduce caregiver stress (Bloom et al. 2012) and alleviate depression and anxiety (Jain, Nazarian and Lavretsky 2014). The FFMQ will provide information pertaining to the extent to which the participants have engaged with the mindfulness component. Furthermore, the separate subscales can provide a deeper understanding as to which facets of mindfulness such an intervention has the potential to enhance.

4.11 Evaluation of Health and Wellbeing Outcomes

Whilst it is important for the sake of feasibility to gauge the extent to which participants engage with the intervention components and the potential positive effect on their associated outcomes, it is also important to consider health and wellbeing outcomes in order to evidence the potential benefits of such a complex intervention. Based on the results from the Stage One qualitative interviews with the informal carers, the outcomes selected for the piloting of the developed intervention were: wellbeing, coping styles and resilience.

Wellbeing relates to the study of positive mental health and is a complex construct that relates to both subjective experience of life satisfaction and psychological functioning (Tennant et al. 2007). With consideration of the positive aspects of the role, the inclusion of a wellbeing measurement allows the pilot evaluation to consider a whole state approach; considering the experiences of caregivers rather than focusing on an absence of illness. An appreciation of not just the changes in negative aspects but an understanding of the influence to the positive aspects is an enhancement to a pilot study, as it provides a greater understanding of the influences of such intervention attempts (Pinquart and Sörensen 2006).

Studying positive effects and aspects of the role in caregivers can be challenging due to a reluctance in reporting, or recognising, these (Wennerberg, Lundgren and Danialson 2012). By measuring wellbeing rather than directly measuring positive aspects of the role, positive changes may be better reported as the caregivers may be more inclined towards congruent self-report. It has also been argued that caregiver burden is the anti-thesis of wellbeing (Stull, Kosloski and Kercher 1994), so any improvements found in wellbeing may be consistent with decreases in burden, thereby providing further potential insight from the pilot study.

Coping styles refer to the ways in which people adapt both cognitively and behaviourally, in response to internally or externally perceived challenges (Mackay and Pakenham 2012). Evaluating coping styles allows an understanding of how methods and skill sets of caregivers have changed following the intervention. To provide a comprehensive pilot study, exploration of coping styles provides information relating to actual behavioural change. These changes in behaviour have the potential to reduce the strains and burden of the caregiving role through providing caregivers with healthy and adaptive ways of responding to challenges. From the Stage One qualitative interviews with the informal carers, it was revealed that the caregivers possessed and utilised many different ways of coping, therefore, a wide stance of evaluation of coping styles would be beneficial.

Resilience refers to the ability to confront challenging circumstances. It is a multi-dimensional construct that involves not only psychological traits, but also the ability to facilitate coping through the use of external sources (Fitzpatrick and Vacha-Haase 2010). Resilience has been highlighted as an important and influential factor in dealing with the caregiving role and relates to not just dealing with the demands of the role but also to thrive, becoming more flexible and healthier (Ross, Holliman and Dixon 2008; Zauszniewski, Bekhet and Suresky 2009; Fitzpatrick and Vacha-Haase 2010).

Together, the measures of wellbeing, coping styles and resilience will provide information pertaining to strong indicators of health and wellbeing and enhance the informative results of the pilot study. Wellbeing considers thriving and health beyond absence of illness (Wrosch, Amir and Miller 2011). This information is imperative in fully understanding the experiences of caregivers and to observe perceived benefits and improvements beyond symptoms. Coping displays adaptive behaviours to deal with challenges. And as not all ways of coping are as beneficial compared to others, it is helpful to also understand how caregivers feel about the coping they use to further understand their experiences. Resilience has been found to increase in caregivers over time, which suggests an on-going process of self-improvement (Richardson 2002).

The capacity of resilience is a protective factor and reveals the ability to endure and to manage. Therefore, these outcomes were selected over carer-centric measures which focus narrowly upon caregiving roles and experiences. Caregiver research in appreciating experiences and caregivers as persons (Hunt 2000; Nolan et al 2004), would suggest that carer-centric measures would be reductive. The caregivers exist within their own right as a person, with their thoughts, feelings and experiences shaping who they are and their perceptions and interpretations of their situations (Murray et al. 1997; Nolan et al. 2001; Nicholas 2003; Ogilvie, Morant and Goodwin 2005). This complexity of experience requires outcome measures that are not as restrictive, and an appreciation that aspects such as wellbeing, coping and resilience will greatly influence, shape, and impact caregivers, and ultimately shape their experiences.

4.11.1 Evaluation of wellbeing

The Warwick Edinburgh Mental Wellbeing Scale (WEMWBS: Tennant et al. 2007) was selected to measure the caregivers' changes in wellbeing. The WEMWBS comprises of fourteen items that include both the eudemonic and hedonic aspects of mental health, i.e. subjective experience and psychological functioning. The tool was developed to provide a wide conception of wellbeing with a single underlying construct. The WEMWBS correlates well with other scales measuring components of wellbeing and also with life satisfaction scales, showing good criterion validity. Social desirability has also been shown to be lower or comparable with other wellbeing measurements which are beneficial for the present study, considering the reluctance or difficulty some caregivers have with reporting positive aspects of the role (Wennerberg, Lundgren and Danielson 2012). The test-retest reliability of the scale is also high (.83) and does not show a ceiling effect which has been a concern with other wellbeing scales (Tennant et al. 2007). High scores denote high reported wellbeing.

Explorations of wellbeing in caregivers using the WEMWBS have shown that the tool can predict psychosocial outcomes quite well, such as anxiety and depression, and negatively correlates with caregiver burden (Cooper et al. 2008; Orgeta, Sterzo and Orrell 2013). The scale has been described as limited in healthy populations of professional caregivers, claiming that scores close to the population median in wellbeing would reduce the sensitivity of the scale (McConachie et al. 2014). However, the authors do not suggest that the lack of change in wellbeing scores may be due to the effectiveness of the intervention their participants received. The informal caregiving population is reportedly lower scoring in wellbeing, however, if such a limitation of the WEMWBS exists, the population tested in this study should not be affected. The scale has also recently been shown to be robust enough for use in diverse populations and provides identification of protective and promoting factors (Stewart-Brown et al. 2011). Use of the WEMWBS will allow exploration of the potential positive benefits of a complex intervention with those caring for relatives with BD, providing a comprehensive whole state approach, thus strengthening the feasibility information provided.

4.11.2 Evaluation of coping styles

The Jalowiec Coping Scale (JCS: Jalowiec 1987; 2003) was selected to measure the coping styles of the caregivers. The JCS provides information not only pertaining to actual use of coping styles but also to their perceived effectiveness. In this manner, it will be possible to measure not only objective behavioural change but also the subjective perceptions of change. The JCS consists of sixty items that outline a potential coping strategy. These represent eight subscales: confrontive; constructive problem solving, evasive; avoiding dealing with the problem, optimistic; maintaining a positive attitude, fatalistic; having pessimistic or hopeless attitudes, emotive; expressing or realising emotions, palliative; doing things such as eating, drinking, taking medications to alter mood, supportant; using support systems, and self-reliant; depending upon oneself. Scores reflect the extent to which a particular method of coping is recognised to be used, and the extent to which it is perceived to be effective.

The JCS was shown to have concordance with the Qualitative Coping Interview and the subscales of coping styles have been shown to be associated with both positive and negative health outcomes (Jalowiec and Powers 1980). In 1995, caregivers of persons with multiple sclerosis took the JCS and factorial analysis of the data showed good internal consistency and distinctiveness (Gulick 1995).

Caregivers of those with dementia showed no changes in the JCS at all following a cognitive behavioural intervention (Gendron et al. 1996), but caregivers of those with BD have also completed the JCS before and after psychoeducational intervention. The authors found a decrease in emotional and palliative coping but also in confrontive coping which was rationalised to have arisen from psychoeducation having made them, aware of the magnitude of the caregiving role (Jonsson et al. 2011). While such evidence is beneficial in furthering the understanding of intervention assistance in those caring for relatives with BD, the restricted forty item scale was used which restricts the potential information provided regarding the effectiveness of the intervention. With the aforementioned factorial analysis finding that the subscales are distinct, a study exploring each of these and their changes following intervention is still required.

4.11.3 Evaluation of resilience

The Dispositional Resilience Scale (DRS-15: Bartone 2009) was selected to evaluate caregiver resilience. The DRS-15 consists of fifteen items each of which is a self-relating statement with which participants select a degree of agreement from a four point Likert scale. The scale comprises of three facets: commitment, control and challenge. First described by Kobasa (1979), these facets relate to being committed and deeply involved in activities, a desire to maintain influence on outcomes and believing change is stimulating for personal growth, respectively. Higher scoring indicates higher levels of resilience across the three subscales.

Some caregivers have been found to become more resilient over time (Enns, Reddon and McDonald 1999; Richardson 2002), and understanding whether this can be induced, and facets in which they change, would be of great benefit in understanding how to instil protective factors in caregivers. Caregiver resilience has been associated with factors such as self-efficacy, self-esteem, care receiver illness appraisal, social support, and a decreased use of emotion focused coping (Wilks and Croom 2007;

Rosenburg et al. 2013) which are some improvements that the current intervention pilot aims to instil through participating in the four components. While caregiving studies that have investigated resilience have opted for other resilience measures, such as the Resilience Scale (S-RS: Neill and Dias 2001), or factors relating to resilience (Bekhet, Johnson and Zauszniewski 2012), the full DRS has been recognised as the best resilience measure (Funk 1992; Sondenaa et al. 2013). The DRS-15 can also be completed quickly and the three separable facts allow for an in depth understanding of which aspects of resilience are affected.

4.12 Chapter Summary

The health and wellbeing outcomes chosen to evaluate the intervention based on the findings of Stage One were: wellbeing, coping styles and resilience. These three outcomes will measure the changes elicited by the four intervention components developed. They encompass not just changes in behaviour but also consider positive aspects of wellbeing to reveal the potential benefits of a complex self-care intervention. Figure 1 presents an illustration of the intervention design with the four components. Also, Figure 2 exemplifies each component and outcome with their associated assessment tool(s).

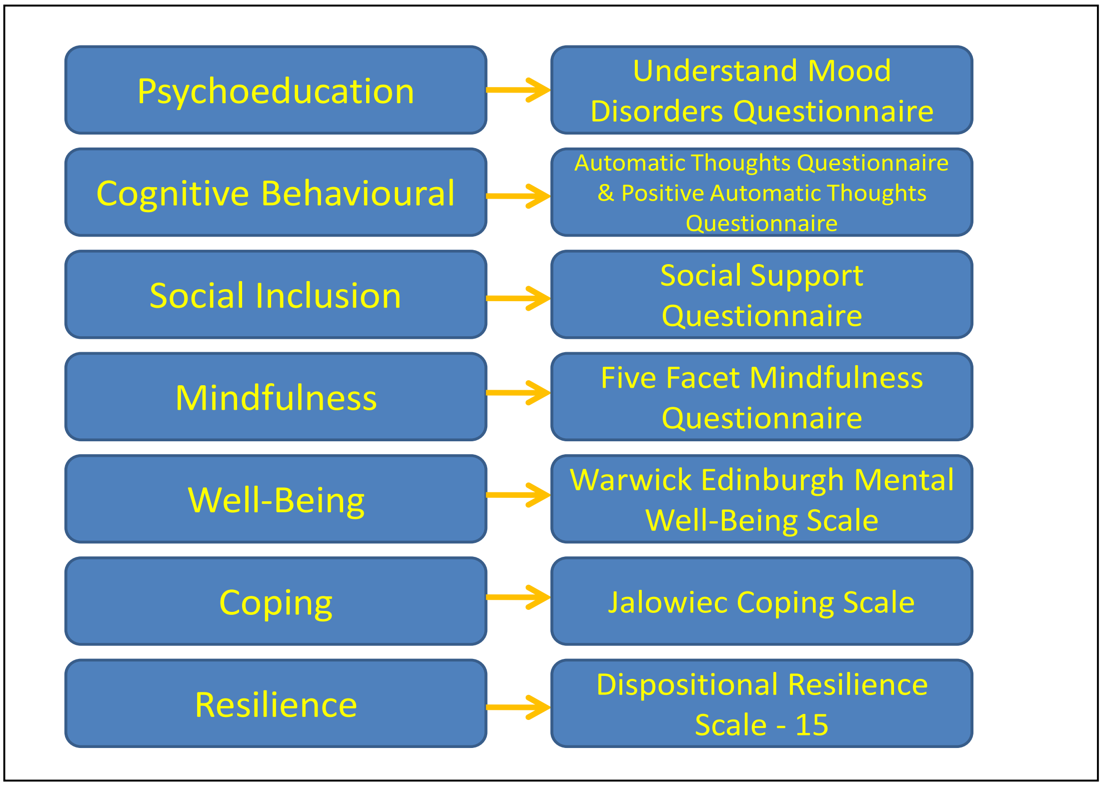


Figure 2: The four components: Psychoeducation, Cognitive Behavioural, Social Inclusion and Mindfulness, and three outcome measures: Well-being, Coping and Resilience, and their associated assessment tools.

Chapter Five: Results from Stage One and Stage Three

5.1 Introduction

This chapter outlines and describes the results of Stage One (qualitative) and Stage Three (pilot evaluation of intervention developed) of the study. In Stage One, caregivers of a person with BD were interviewed and qualitative analysis was performed on transcripts undertaken to elucidate lived experiences. The work in Stage Three involved the longitudinal pilot of the intervention developed, and evaluated based upon the results from Stage One.

5.2 Approach to Presentation of Stage One and Stage Three Results

Although each informal carer's experience of taking care of a relative with BD was unique to him or her, common patterns were present in the accounts of their experiences in the study. The emergent themes from the qualitative interviews in Stage One of the study are used to enlighten how they have lived these aspects of the experience, which was the aim of Stage One. The themes here were developed by the research question asked and analytical interpretation of the data collected.

Firstly, the presentation of findings starts with the eight key themes elucidated from participant interviews in Stage One. Each theme is explained with a discussion of its constitutive sub-themes. Following a brief introduction naming the theme, a topic sentence is given for explanation and followed by quotes to illustrate the theme. The names used in this part of the thesis and elsewhere are pseudonyms for protecting the anonymity of participants in the study. The themes are fully discussed in Chapter Six. Secondly, the Stage Three results which involved the longitudinal pilot of the intervention developed, and evaluated based upon the results from Stage One are presented. The Stage Three Results are based on quantitative analysis and follow after the Stage One Qualitative results.

5.3 Provision of Care

In the role of providing care for their relative the carers reported providing various forms of assistance and support. The most common form of care provided was with basic functioning to aide their relative to engage in and complete activities of daily living.

5.3.1 Assisting Basic Functioning

The caregivers were involved in day to day tasks of rudimentary function for their care receivers and were required for not just the execution of these tasks but also the instigation in a lot of cases:

> *"If...even sometimes when he's relatively well he won't decide to eat. He'll eat only if he's given some encouragement and a meal's organised and so on."* – Julia

> *"…it's just lots of things, you know, he'll forget, you know, umm so I have to be there, sort of remind him, you know, 'Do this.'*

> *or 'You've done that.', 'You've left this.' Or you know, that sort of thing."* – Elaine

> *"And she finds shopping extremely difficult so she frequently phones me up and asks me if I'll, have I done any shopping and I know then that she wants to go shopping. She can't cope with supermarkets."* – Donna

5.3.2 Emotional Support

Care was also provided on a more interpersonal means through emotional support:

> *"And I think at some level I was a sheet anchor. I'm always there for when things get too much."* – Violet

> *"…this is a week that she is working and she nevertheless phones several times a day, but when she isn't working she almost always comes to us*." – Donna

The caregivers provided more than support with tasks, but also support on a deeper and emotional level. They were expected to provide emotional relief when their relative required it, and also to provide this support unconditionally and consistently.

5.3.3 Adherence to Treatment

The caregivers also ensured that their relatives were consistent, with their adherence to their treatments:

> *"I think, if I wasn't there, if I wasn't there to see to all his daily needs, emm, his medication, his appointments, different things, I don't know what would happen really."* – Elaine

> *"I've stayed self-employed so I can be freed up easily if I need to be and it would give me far more peace of mind to work for someone…but I've had to sacrifice that to be flexible enough so that I can go to appointments with (relative) or pick up meds, or go home during the day if she's not so well."* – Harry

Adherence to treatment plans such as making appointments with general practitioners, commuity psychiatric nurses and psychologist along with medication regimes, became a shared responsibility of the caregivers. They had involved themselves in the maintenance of the processes around adherence and viewed them as important. In some cases, the caregivers viewed close observation to treatment as more important than those they cared for. Ensuring treatment adherence was a task undoubtedly created when their relative began treatment but other areas of care involved the carers taking more, if not most, of the responsibility for once shared areas of live such as familial obligations.

5.3.4 Familial Support

It was not the case that the caregivers thought they were looking after family when they wouldn't have otherwise but rather that they had imagined their role to be different, before their care recipient became ill:

> *"We'd had two children. I was really depending on him because he was much better with the children than me. I'd always had career aspirations and never been particularly maternal kind of person."* – Julia

> *"It was down to us to help with the kids. We wouldn't have just left them but it was down to us and that was that. We'd pick up from school, feed them, make sure they had homework done. We basically took over at points."* – Tim

The extent to which the caregivers were providing support to other family members was far greater, than if their care recipient was well and able to assist, resulting in larger proportions of care to family, or the necessity of different and more actively involved roles than imagined.

5.3.5 Financial Support

Another area the carers provided assistance with is that of money through financial support:

> *"She's always running out of money, she can't manage money, at all really. I mean, she tries hard and the banks are good to her. They are very good and very helpful but she can't manage money. If she gets money, she spends it."* – Donna
> *"But yeah, I'm working to keep us… It was a big change going down to one wage. It was tight for a while but we've learned to make changes."* – Harry

The need for provision of financial support arose in a few ways. The carers' relatives had in some cases stopped working when they became unwell, and reduced the household income or financial support, and/or intervention was required when their care recipient had spent excessive amounts of money during a manic phase of their illness. The caregivers felt obliged to ensure a decent standard of living through financial means in opposition to reduced income.

5.3.6 Being On Call

Another obligation experienced by the carers was that of being on-call, i.e. being with their care recipient as much as possible:

> *"Well, I'm with him twenty four seven…Which has been a real witch's brew because there's been no buffer or protection, you know, I've been locked with this, this illness of his…"* – Violet

> *"I was aware that he was ill … [which] made me really watch him very very carefully, you know, and was very much aware about where he was and what he was doing. I'm still like that. I'm still thinking just now, he's downstairs having a coffee, I know he's alright, you know but it's always there at the back of your mind."* – Elaine

> *"There are these constant little emergencies that I need to bepresent to attend to."* – Donna

The process of being on call arose from feelings of guilt and fear when not with their relative in case their help was needed or symptomatic behaviours such as suicidal ideations took effect. Constantly striving to be at their relative's side in such a way impacted the development of the caregivers' personal identities and greatly restricted personal space, but conversely added to the carer identity and sense of duty. Being on call appeared to be an incessant feeling experienced by the caregivers and seemed to continue despite periods of euthymia in their relatives.

5.4 Caregiver Knowledge of Bipolar Disorder

The displayed levels of knowledge of BD varied between the caregivers in regards to both the epidemiology and aetiology. The causes of BD that the carers reported tended to rely upon inherited factors and focused on atypical behaviour in the brain. The participants relied upon their own experience with their relative to make sense of and describe the symptoms of the condition:

> *"Well, there's undoubtedly an inherited element, umm, and we can see that through the family in fact, through his side of the family."*– Violet

> *"I know that it's associated with psychotic features and that it's different-ish from schizophrenia though there's still enough overlap for people to make mistake in diagnoses. But I mean I'm reassured when (relative) says that the voices that he hears, sometimes they're usually talking to him, he's not overhearing the, kind of, third party conversations that seem to be a feature of schizophrenia…"* – Julia

> *"...probably it's the chemical imbalance in the brain and it's just, something that...I think probably people are probably born with these disorders and maybe, well this is my interpretation,*

> *I'm not sure if it's right but I feel that probably there's a trigger that probably sets of these sort of chemical reactions or maybe that's not true but emm, but I think it's always maybe lying dormant for quite a number of years."* – Elaine

> *"I know it's to do with the brain and that it means your mood goes up and down. From (relative)'s behaviour the ups are like a lot, no, too much energy and too many ideas and no looking at consequences and the lows are sort of like depression really. I wouldn't say there's much difference."* – Harry

There was, however, consensus in the understanding of the longevity of BD. Understanding that BD could be controlled rather than cured was well displayed through the participants' interviews and this knowledge seemed to be coupled with an element of acceptance to the changes that had occurred in their lives.

> *"…and now being quite resigned to that fact that it is never going to be back to what it was, that I'm living with somebody who has a long term condition that's never going to be satisfactorily resolved. That the way in which I'll have the nicest life and he'll have the nicest life is for us to be able to negotiate a way through that."* – Julia

> *"It's the ways things will be now. It's not something that just goes away. It's better than it was and it could still improve from where she is at now but it's never not going to be here."* – Tim

> *"Umm, it's lifelong. It's incurable. It's symptoms are controllable, with a medication regime which he does accept…"* – Violet

Apart from gaining understanding through experience, seeking external information about BD could be found to be difficult and confusing. The caregivers were both unsure as to where to find information and also how to know which information was accurate and reliable.

> *"Knowledge is power because, as I said previously, I nursed all my life but I didn't really know a lot about mental health and I still don't know a lot about mental health. There's still a lot to be learned. A lot."* – Elaine

> *"I'm still hazy on the causes because I think generally it's hazy. I suspect that psychologists themselves haven't yet put it all together, quite honestly…it all seems to be very hazy so I wouldn't say that I really know that much about it."* – Donna

Overall the participants' understandings of BD ultimately stemmed from their own experiences of caring for their relative. This would suggest that at the point where the participants were first required to fulfil the caring role, their knowledge was limited and had to develop over time. The sources necessary to gain further information were not seen to be accessible by the participants and therefore not utilised as much as they could potentially be.

5.5 Positive Aspects of the role

Positive aspects of the role referred to potential beneficial aspects that emerged from the caregiving role. Some of the participants found it initially difficult to recognise any of these but were facilitated to recognise four areas in which their lives could be perceived as being a good thing despite the negative experiences of the role.

5.5.1 Quality Care for Care Receiver

Quality care for the care recipient was a reflection of how the participants wanted the highest standards of care and safety for their relatives and felt that they themselves were able to provide this better than someone else. The participants seemed to take solace in this as it meant that they were necessary for the on-going health and safety of the person they were caring for:

> “*I know that I love my husband and he isn’t in the gutter or dead which would both have been on the cards, or indeed, in prison, because I have stood by him and I do stand by him*.” – Violet

The caregivers felt that if they were not providing the care they had done, then their care recipient would not be as well as they were, and this realisation caused the role of providing care to be one of unquestioning necessity rather than choice:

> *“His choice would have been to drown because he’s always been drawn to the water and he did tell me at one point that that would be his choice for how to do it. So I think probably if I hadn’t been there for him, he wouldn’t be here. So it wasn’t really a choice, it just had to be done and that was it.”* – Elaine

This sense of duty allowed the caregivers to feel that what they did was rewarding, in the sense that they had comfort in knowing they were doing the best they could for those they cared for. Despite this being coupled with a sense of obligation to adhere to the role of caregiver, it led to another positive aspect from which meaning was found in the caregiving role.

5.5.2 Meaning Through Caregiving

Finding meaning in the caregiving role is an aspect that developed over time with the caregivers as they accepted their role as ‘a carer’. The acceptance of the situation and role they were now in, led to the mentality of appreciating who they were and what they did:

> “*There’s maybe something between us now that wouldn’t have been there. Because I’ve had to not just be a husband but also care for her, I think there’s a deeper bond almost, actually no. Not a deeper bond, but another bond. Because the husband and wife bond grew weaker but in its place this one came up. Over time, I suppose.*” – Harry

In recognising the value of their efforts, it was possible to take solace in knowing the efforts they were making were for beneficial purpose. Through accepting oneself as a carer it was possible to find a greater sense of purpose to the care they provided and the role they led.

> *"I think I get the satisfaction too that I think I'm helping him in some way that I'm there for him. I've been a carer all my life so...but funnily enough, caring and being a wife is two different things."* – Elaine

5.5.3 Personal Growth or Change

The experiences of caring for their relatives had been accentuated with hardships, struggles and very mixed emotions through the years. But from these hardships the caregivers recognised changes in themselves. Personal change or growth was very strongly recognised by the caregivers and they had noticed a developed change in themselves as a person through the process, and took gratification from this:

> *"I think that I've learned some stuff about how to deal with people who are distressed and I think that has improved some of the things about the way I interact with other people. It's improved me in that way."* – Julia

> *"You can either let it consume you or you can adapt. I can see now that I'm a stronger person in many ways that I wasn't before. It's a good change for me but it was a necessary change I think."* – Tim

Changes that occurred gravitated around social ability: such as patience, acceptance and kindness, and personal skills: adaption, problem solving and awareness. The personal development perceived by the participants was proactive to their role. They could perceive the benefit of being a 'better' person but for the most part recognised this as a required process:

> "*Now I've come to the conclusion that when you're going through the furnace you're either consumed by it or you're strengthened by it. And I hope I was able to come out tempered and weather the storm for both our sakes.*" – Violet

5.5.4 Recognising Strength of the Care Receiver

Conversely to personal change, the caregivers also took satisfaction from seeing the strength of their care recipient. Having seen them experience and deal with so much had allowed them to realise aspects of their relatives that they had not seen before, and felt a sense of pride and respect from this. Being with their care recipient throughout their experiences provided them an insight in to their character that they had come to appreciate:

> *"The other thing that makes it worth it for me is seeing his courage in facing it. That he continues to try to struggle...umm, to get himself out of the bit, you know? He will try changing his lifestyle; he'll try all sorts of things. Umm, not always successfully but he will actually approach the fact that he's ill with courage and with resilience and I do admire that*." – Julia

5.6 Negative Aspects of the Role

Negative aspects of the role encompassed and specified the challenges, strains, and burdens that caring for a relative with BD produced. The subthemes for negative aspects were generally stronger and more prominent than their positive counterparts and required less prompting and exploration to ascertain.

5.6.1 Dealing with Challenging Behaviour

The most reported challenge for the caregivers was that of dealing with challenging behaviours from their relative. Dealing with challenging behaviour refers to living with, observing and dealing with conduct relating to the effects of BD. These behaviours tended to focus on suicidal ideations and intentions, the high-paced and sometimes irrational actions of mania and the withdrawn and depressed effects of depression:

> *"The most challenging this is trying to maintain a reasonable relationship. She would scratch at me verbally. I was seen as the enemy. It would come out of nowhere."* – Donna
>
> *"When things were worse and she would talk about suicide and that, I found that hard. I hadn't a clue what to say to someone like that, I'd never heard someone be so abrupt about such a thing*." – Harry

Coping with the variability and dynamism of behaviours was very difficult and the added effects of not being able to associate with the emotions and thoughts of their care recipients proved to be challenging. Attempting to pre-empt and live with these behaviours contributed to the hardest elements of the role to endure, and took up a considerable amount of effort and time. This dedication to dealing with the effects of the BD led the caregivers to feel that, they had had to sacrifice parts of themselves to allow for the resources to cope and continue to support their relatives. This self-sacrifice led to a loss of identity for the caregivers.

5.6.2 Loss of Identity

> *"I had a lot of negativity and I lost my identity completely. I wasn't me at all because I've always been a doer and also had a lot of energy and I need to be doing things so I think I came to a bit of a grinding halt. I was very down."* – Elaine

The very role of carer had become part of their lives but at the expense of the lives they had led, and wanted to live. Aspects of their own ambitions and desires had to be forgotten or side-lined for the sake of the health of their care recipient and led to a feeling of emptiness through a lack of self-fulfilment and thus self-identity. In focusing so much upon their role as carer, the caregivers expressed a great deal of worries and concerns.

5.6.3 Caregiving Concerns

The theme of concerns encapsulates the on-going worry, doubt and fear that the caregivers expressed regarding the future. Concerns focused on the health outcomes and actions of their relatives and what would happen to their relatives if they were no longer there or able to care for them. The uncertainty felt around these issues caused distress for the caregivers as they felt inadequately prepared for eventualities that they feared occurring:

> "*She could not exist without us. Equally, if we die the day after tomorrow, we know that the money we leave her will be gone the day after that. So there's no use thinking to yourself, 'Oh, she'll be alright once she gets some money.', she won't. She's always going to be in trouble financially. She can't get a job that pays and if she gets money, it goes. And there's still a lot of eccentric uh…decisions that she makes in her life. They're not as disastrous as they used to be but they're still there*." – Tim

> "*I'm still worried in the back of my mind that one day she'll get a bad low and try kill herself. She's a lot better than she used to be and even the psychiatrist told me that I shouldn't worry about that but you still do don't you? It's the unknown.*" – Harry

5.6.4 Being Bound to the Care Receiver

Whilst concerns focused on the potential future, the caregivers expressed a great deal of stress arising from feeling compelled to be with their care receiver as much as possible to ensure they were okay. This tended to be cast against the need for respite and having their own time, but these attempts were met with self-induced feelings of anxiety and guilt at being away from their relative. This is represented by the theme of 'Being Bound' to the care recipient:

> "*It restricts my freedom to do what I want to do. That's not to say that I'm not enjoying life at the moment, I am but I'm restricted. I mean, it's a necessity that I should be there if*

anything happened and you do worry that things will happen if you're not there." – Donna

"Even if he's with someone that I know, I spend my whole time thinking if he's okay, if he'd be honest with them if he wasn't. I find it hard to...to not be there. It's just, what if something happens, you know?" – Elaine

"She went to a friend's house for coffee and I was going to relax and get some things done but the whole time I felt like it wasn't right. I need my own space and things for me but I just don't get that. I even had to work for myself so I can have the ability to take time off when I need to, when she needs to." - Harry

5.7 Perspectives of Life Changes

Becoming a caregiver and the impact of the role had altered the participants' lives in very dynamic ways. A notable and frequently mentioned milestone was that of the diagnosis of their relative.

5.7.1 Care Recipient Diagnosis

The caregivers expressed a need for greater consideration for those in their role at the time of a relative's diagnosis. Feelings of confusion, grief and shock accumulated into an overwhelming event in which the caregivers were lost and unsure what to do. Their relatives had displayed symptomatic behaviours prior to diagnosis but having a clinical verdict seemed to both clarify and actualise their situation as informal caregivers:

"I'd got in there and umm, nobody really talked to me or took me aside and I strongly feel that the carer, the person closest to the patient, right at that point of crisis when it's all happening, whether or not they know the diagnosis, they need some TLC." – Violet

> *"I remember walking out of (hospital) after seeing him for the first few visits and sitting in the car park in the car with tears just streaming down my face because I just didn't know what to do, I didn't know how to be...umm...there wasn't anybody who was paying much attention to me because all the attention was on my acutely ill husband that, you know, and people were saying 'Are you all right?' at that kind of basic level but I didn't feel there was anybody who understood the position I was in and I didn't know anyone in the same boat."* – Julia

> *"…but when I was told that [he was unwell], it was the biggest shock to me and probably the worst day of my life"* – Elaine

Prior to receiving a diagnosis, the lives of the caregivers and their relatives were different. The variation in experiences depended upon the proximity of diagnosis for their relatives with close proximity fostering a sense of loss or grief that arose from feelings that their loved ones and lives had changed:

> *"I think that was one the hardest bits come to think about it, was realising that our old way of life was gone. There wasn't going to be any way that we were going to be in a situation where (relative) was completely fine and we'd have no worries."* – Harry

> *"We were close, loving, trusting. Utterly faithful. We were lucky. We got along really well together…which, of course, stopped when he fell ill."* – Violet

> *"We had a good relationship but I suppose a relationship in which he was able to, umm...enjoy things and take a lead in a way that's very different from what it's like now."* – Julia

Or where a greater deal of time separated the onset of their relatives' BD condition and diagnosis there was a greater focus on how a better understanding, and the beginnings of help had made a difference to their loved ones:

> *"Before she was diagnosed I mean that was difficult, to put it mildly. We'd have endless rows and...umm, she'd march out of the house and it was just a series of endless battles really."* – Donna
> *"It's better now but that's not because of us. I'm sure it's because of the medication and the diagnosis."* – Tim

> *"…probably I was caring for him before but didn't actually realise it because I'd done quite a lot for him before I realised he was ill so my role as carer, I don't know, was always there. So, being a carer, being a wife, I mean it's only recently that carers have had a label as carers."* – Elaine

Where relative onset of BD and diagnosis were more separated chronologically, the caregiver focus was more inclined towards noticing the difference that commencing and receiving treatment had on their care recipient's health rather than focusing on the changes instigated by the illness onset that caused changes in how they personally perceived them.

5.7.2 Disruption to the Future

When discussing the future, the caregivers referred to how plans had been changed or completely ceased due to the impact and repercussions of their care receiver's BD illness:

> *"...and you eventually learn to cross things off the list but, umm...you're not always aware what the circumstances will be like. They're not what they were going to be though."* – Julia

> *"I mean, what is normal? I said to her 'Your life will never be the same.' From that diagnosis or that whatever happens in her husband's life that tips him over, that's it the life you had before*

> *is non-existent because you've got to live a different life entirely*." – Elaine

> "*You can't live in the moment anymore, it's always about looking into the future and planning the worst. That isn't half as much fun, I'll tell you that."* – Harry

The role of becoming an informal carer affected the future through limitations and changes necessary for the health and wellbeing of those they cared for. The care givers seemed to have, in time, realised that their lives were not going to continue as they had previously planned, and that these changes were necessary and on-going.

5.8 Coping Styles

The informal caregivers had a plethora of experience between them and ten coping styles were identified. Coping styles were identified when participants seemed to use these adaptions to deal with the consequences of their roles.

5.8.1 Empathy for the Care Receiver

The most emergent of these coping styles was empathising with the care recipient. The caregivers found it beneficial to try to understand things from the perspective of those they cared for and tailor their actions in accordance; empathy for the care recipient:

> "*I think he's short changed. I think he's suffered for a long time. I don't know exactly what it's like to be in his head but I don't think it can always be very pleasant for him. It's cut him off from me in some ways, you know. He can't...he's not in an emotional place where he can turn to me and I could just put my arms round him and comfort him.*" – Violet

In some ways, the empathy experienced by the caregiver provided them with elements of insight that aided the role through increased patience and understanding. This was represented well through an example given by one of the caregivers in regards to assisting with gardening:

> *"Now, previously we would, in the end, have pitched in to do something about it. But we would have resented it because we'd have said she's perfectly capable of doing it herself. Now we are more aware of the character of the illness we will pitch in. Maybe we won't pitch in any more than frequently but we won't resent it."* – Tim

5.8.2 Self Awareness

It was not just by trying to better understand the point of view of the person they provided care for that was found beneficial, but also a better understanding of self; self-awareness:

> *"I mean, I have no illusions about the actual caring, we had to take over, totally. And we still have to, to a certain extent, you just have to be very tactful about it and know which things you should do and which things you should not do, out of fairness."* – Donna

Increased self-awareness facilitated the caregivers' abilities of introspection which allowed them to monitor their own behaviours towards their care recipients.

5.8.3 Communication

This awareness also led to the understanding of the importance of talking with one another, and trying to hear what their care recipient had to say was also strongly portrayed; communication:

> *"Saying things like 'It'll be fine.' Or 'Don't be so stupid.' don't do anything or can make things worse. I guess you've got to listen to what they say and let them know you've heard them otherwise there's a chance they're just not going to try talk to you."* – Harry

Communication aided the role of the informal caregivers through being better able to act in ways that were based on the increased levels of self-awareness, such as understanding that bandaging statements, whilst almost impulsive to reply to, served little process utility in trying to engage a dialogue with their care receivers. Through open dialogue, the informal caregivers could enable discourse that is open, honest, and attentive to the care recipient to display their understanding:

> *"…he never told me he was thinking about suicide, he does now. He's quite open about his condition."* – Elaine

> *"…she'll talk about it, she recognises where she is and that has made a colossal difference, you know, that recognition because before she didn't realise there was any problem whatsoever. We can talk now. It makes a difference."* – Donna

> *"And I don't tell him what is obviously wrong is right and that's not been easy. So naturally, I'm quite proud of myself for that."*
> – Violet

Being able to talk with their relative allowed the caregivers to make their point known whilst at the same time being able to listen, providing a balance between self-serving and supportive discourse. Their relatives initially tended to hold back when talking about their BD condition and the dichotomous carer/relative role that had arisen through this, but in time, a dynamic between the two (caregiver and relative) developed, to allow for productive and facilitative communication.

5.8.4 Acceptance

For the carers themselves, a coping style that appeared to have developed over time was that of acceptance. Acceptance refers to the 'coming to terms' with their lives and roles as carers, having acknowledged the changes that arose with the caring role. These changes refer to the identity of the relatives themselves as 'carers', the altered dynamic and relationship with their relative, and strains in areas such as occupation, health and finance. Acceptance could portray an element of resignation where the participants felt they had little control or choice over an inevitable situation:

> *"[Life is] much more low key and much more dutiful I suppose. He's still my husband and I still love him and we still have a good relationship in that sense but on top of that is the feeling that, in some ways, I am his carer."* – Julia

Or, arose from experiences that had shaped a new, yet definitive situation or identity for the carers:

> *"So, being a carer, being a wife, I mean it's only recently that carers have had a label as carers. Before, you were just a wife and you looked after your husband so I don't know about the transition between the two, I don't know if there was such a transition really."* – Elaine

> *"I think understanding the situation and realising that it's what we make of it now that's going to matter. No matter how much I want things to go back to the way they were, it's just not going to happen."* – Harry

The process of attaining a sense of acceptance may have varied across the caregivers in the study, but possessing a degree of acceptance over a life that had clearly changed allowed the relatives to retain an element of control over the situation within themselves. Understanding and appreciating that things are the way they are, allowed a clear basis from which to progress, that was not skewed with anxieties, doubts or contemplations based in possibilities rather than the facts of the here and now. However, not all efforts of coping were as active.

5.8.5 Avoidance

The caregivers also reported attempting to cope by ignoring their thoughts, feelings and situations or 'letting things play out' without personally intervening: avoidance:

> *"…it just didn't feel like I had it in me to do anything about it. It annoyed me, very much so but I just couldn't bring myself to get in to something else again."* – Donna

> *"None of that would happen now, but at the time it was very different. I felt like saying "We're off, goodbye. We'll send you a postcard from Sydney."* – Tim

Avoidance was used by them when they felt they had neither the strength nor the ability to overcome challenges. The use of such avoidant behaviours seemed to be coupled with an underlying frustration at personal inaction, despite having arisen through not feeling able to act in the first place.

5.8.6 Enjoyable Activity

Not all attempts to focus on something else had such a negative effect however; many of the relatives had found solace in engaging in hobbies and activities from which they gained personal pleasure: enjoyable activity:

"…well I think you have to learn to take time out for yourself. Find something you enjoy. I have these model ships that I do and it's good because I can get my own space but still be at home so I don't feel guilty for being out the house." – Harry

Engaging in an enjoyable activity provided a component of space and respite for the participants and allowed them to spend time and focus on themselves and their needs. Spending a great deal of time concerning the lives of their care recipients, the care givers sought to maintain an element of their lives they enjoyed and generally used this activity to ensure some time through which they had to call their own, and do what they wanted.

5.8.7 Peer Support

It was not just on their own that the caregivers coped, but also with others who had been through similar experiences to themselves: peers support. Peer support offered several benefits: a place to talk and be understood, feeling less isolated and learning from the experiences of others:

> *"I think there's that combination of seeing other people surviving and thinking 'Well, they're managing alright, maybe I'll get there.'…people suggested that you did or avoided doing have been very helpful over the years so being in contact with people who can feed you that kind of snippet that you can use or not use is really good"* – Julia

> *"I think it's working through those processes and having somebody who can feed in, 'This might help you now.'"* – Donna

Spending time with those who had been through a similar process enabled the participants to share in the experiences of others and through these, feel less alone in their own endeavours and find out what other people found useful. Hearing what others had been through and how they had dealt with these challenges let the caregivers see that there were other people out there going through similar experience, and seeing that they had survived these showed them an element of hope to their own situation.

5.8.8 Problem Solving

The experience of others fed in to the dynamic process of evaluating situations and formulating reactions: problem solving:

> *"…you've got to try things out and see what works. What works at one time may not necessarily work the next time so it's more*

> *of a reactive process. You learn how to adapt and how to change to suit the changes."* – Tim

> *"I mean, it's all about planning really but just to assist with that planning and to be able to do that in a situation where I can say 'but the thing that will drive me mad about that is that I won't be able to put up with how (relative) looks at me when I do that' you know, and so it's being able to acknowledge the difficulties in that sort of separate relationship."* – Julia

Problem solving developed over time and with practice. The ability to assess a situation and evaluate the requirements and limitations of action required a decent understanding of themselves and their relative. The product of this would therefore be an adaption or change that would alleviate or control negative aspects or consequences, with the basis for this change having emerged from active assessment on behalf of the caregiver. Problem solving was well represented in this manner through awareness of care receiver triggers:

> *"I know if the dust mites raise their ugly heads that we're in difficulties but he isn't aware of these things and I think it's a crucial part of his treatment that that be provided."* – Violet

> *"…I have to be there for her as well, you know? I'll ask her how she is and try to make her feel better if she not in a good mood or she's not got that oomph in her and I know that's a bad sign."* – Harry

Knowing which signs and symptoms to look out for in their relatives BD condition meant that, the caregivers could better predict possible upcoming difficulties through changes in behaviour and/or mood. Through understanding what was to come, it was easier for them to predict the outcome and therefore to adapt to it.

5.9 Support Received

Support from others consisted of perceived external assistance by the caregivers. Perceived support ranged from having someone to talk to and unburden themselves to having help with providing care for their relative. Family, friends and professionals were the groups spoken of by the caregivers, all of whom received both positive and negative feedback.

5.9.1 Family and Friends

Support from family arose from those in the same household or other members of whom they did not live with:

> *"My sister…came and spent long chunks of time with me and the children and just provided a routine in the household so when I felt that everything in my life had gone completely unstable, I had somebody who was not being judgemental, who was being supportive..."* – Julia

> *"…having a granddaughter on the spot is a great help. It doesn't let us get away to wherever we fancy but it's a great help day by day. It means we don't have to do everything that we need to help."* – Donna

Having a family member's assistance, allowed for an unburdening of duties, and provided a sense of external normality for the caregivers. However, in some instances familial intervention was not seen as positive:

> *"They don't understand it. There's no effort made from them to understand it. It's all the stigma around mental health and they can't see what he's going through so I find myself guarded when they talk to him about things."* – Elaine

Overall the majority of support received from family was spoken of positively. But in the instances of negative reporting, the cause for this tended to be from the perception and the approach that the family member intervening was operating from, that of ignorance towards mental health and therefore thought to be counter-productive. The same response was purveyed in regards to support from friends:

> *"It can be as simple as having someone to talk to. For them to be there for you so you know that you have somewhere you can…vent, I suppose. I have good friends. They help a lot."* – Elaine

> *"I sought help from a close friend and he was great. I was constrained at the time with work and he would drop things off or pick things up and would check in by on (relative) when I couldn't. It was immensely helpful. Very much so."* – Tim

Positively perceived assistance focused on assisting the caregivers through providing someone to talk to, allowing them the opportunity to talk openly and honestly about their experiences, and also through assisting in tasks affiliated with the provision of care to their relative. The participants found support useful when it focused on routine tasks that they would normally do. This allowed the participants to know that their relatives' needs were still being met whilst not having to actively engage in these on-going yet necessary tasks. Support from friends was viewed negatively when the friend displayed a lack of empathy or understanding towards mental health and its consequences. They regarded this approach and attitude to be less helpful and felt that a lack of appreciation of the challenges they and their relative faced were a hindrance to the overall care they aimed to provide.

> *"You know, at first there's a great rush of friends and support and what have you but as it goes on, I think people feel 'I can't solve this problem.' And they just see 'problem' or it's uncomfortable."* – Violet

> *"Most people haven't got a clue. Even when you try to explain to some people you think would, but no."* – Donna

5.9.2 Mental Healthcare Professionals

In regards to professional assistance, the informal caregivers assumed that those working with their relative would have a competent basis in how to effectively engage with those experiencing a mental health condition. The negative experiences of support from friends and family was not expected from healthcare professionals, as they expected a higher regard from them in relation to providing support. Help from a professional was perceived as positive when they treated the carer and their relative as individuals and with respect:

> *"So it helps to feel involved but being but having your own point of view treated with respect as a carer is also really important because it helps you to think well actually I'm doing something quite useful here in providing this kind of feedback."* – Julia
>
> *"It made such a difference to have someone talk to you and actually listen. There weren't many who'd bother to take the time, they were all too busy but I was more able to talk to her and ask about caring for my daughter. I'd never had been able to have that before."* – Tim
>
> *"(Relative)'s psychiatrist have been good for her. She thinks differently now. She understands it and the more we've learned the easier it is to live with and deal with."* – Harry

Conversely, when the participants felt that their relative was not being provided with adequate and requisite care, or that they themselves were being dismissed, their opinions of professional assistance were far less positive:

> *"The only help that's been was getting her medication right. Nothing else at all, nothing. If you have to do a scale of minus ten to plus ten, I'd say it's way down in the minuses…there is no attempt whatsoever, even to be friendly. It's quite*

> *extraordinary. The staff make no effort whatsoever to talk to the family. Nothing."* – Donna

> *"Yeah, he's still receiving treatment and things but it's sort of reactive. They've not been taking on board, really seriously, what I've been saying. I've even had the CPN saying 'Oh, nobody else has complained'. It's been a case of let him collide with disaster and then we might do something. They're hiding behind some sort of warped political correctness."* – Julia

> *"If someone had said that there were behaviours and triggers and I could learn about them and try to help (relative), it would have helped us both so much. As I said, I tried to speak to her CPN about it but I felt like I was just being brushed off like it wouldn't make a difference at all."* - Harry

5.10 What's Wanted

The informal caregivers expressed wants and desires regarding their situation and in relation to how they had been supported in the past. Many wished to have their relative well again or have the person back that they remembered them to have been, prior to their illness. However, they did admit that, that would be beyond the limits of what to ask for, but did mention the perceived need for carer-centred support:

> *"So, quite apart from the…the emotional, if you like, counselling TLC side of it, somebody to say 'You're having a horrible time at the moment', you know? 'Come and sit down, we'll talk about what it's like when someone disappears into a mentally ill state, it's not that he doesn't love you. He isn't capable of demonstrating it.' You know, all the stuff that comes with it."* – Violet

> *"I was saying to my husband, what we would have appreciated would be the equivalent of a CPN but for us."* – Donna

> *"Most of what I've come to learn is off my own back and through years of trial and error. When you think that that 'error' comes at the cost of the health of someone you love you wish there would be an alternative."* – Harry

> *"We also have to have support, especially out of hours and especially at weekends because that's very, very lacking in all areas really."* – Elaine

The informal caregivers identified a specific need for caregiver support possibly from a dedicated source to assist them. Aspects such as dealing with the transition from relative to carer and how to perform their role well were suggested. Despite the external carer support networks such as carer centres and peer groups, they felt that support was needed from the healthcare teams, and that this could be a mutual relationship, with professionals providing support but also allowing the carers to share their experience and knowledge of their relative to aide their treatment.

> *"I think we need a voice or for somebody to recognise what it is we do. It took me a long time to accept I was a carer and now that I have I don't envy those about to go through what I went through."* – Harry

> *"I think the professionals in (hospital) might have done more. Might have done more recently to explain, 'Look, this lady is bipolar. This is what you must expect, you know. Not even that. Nothing. So you just have to do it in the light of day."* – Tim

> *"…if I'm going to be doing this, how am I going to do it better and with less distress for me and for (relative), you know, and the people we impact on. But I mean, some of that help a bit earlier on would have been good."* – Julia

In summary, Stage One qualitative results highlighted eight major themes of lived experience: Provision of Care, Caregiver Knowledge, Positive and

Negative Experiences, Coping Styles, Perceived Support, Life Changes and What's Wanted. The Stage Three Quantitative results follow.

5.11 Presentation of Stage Three Results

The pilot study of Stage Three provides information concerning the capacity of undertaking of a larger scale version of such an intervention through feasibility, acceptability, meaningfulness and effectiveness. This information is provided from recruitment and attrition/ retention rates, feedback from participants regarding ease of use, understanding, applicability and usefulness of components, and the outcomes of the validated assessment tools to provide potential positive effects.

These are presented below under the headings of feasibility, meaningfulness and acceptability, and effectiveness.

5.11.1 Feasibility

In terms of feasibility, forty informal caregivers were recruited overall from contact with carer centres, online advertisements and press releases. Forty nine carer centres were contacted, eighteen of which responded (37%). Responses were from the appointed person of contact for each centre. Acknowledging the recruitment request for the study, persons of contact generally replied to say they would make those eligible aware of the opportunity. Two of the centres contacted had no service users who met the criteria of caring for a relative or spouse with BD. The majority of the informal caregivers for the study were recruited through this means (67.5%) with those who made contact having seen the study advertised online (22.5%), and from newspaper releases (10%) comprising the remainder.

Across both the interventions and control groups, participant drop out across Stage Three was 35%. There was an initial dropout of 13% in the intervention group and complete retention in the control group. During the four months between baseline and follow up, the intervention group experienced a 35% drop out and the control group 10%. The only reason given for withdrawal from the study was heavy caring commitments, a reason provided by a single respondent (See Figure 3). Such a dropout rate is better than anticipated given that of previous research (Bland and Harrison 2000; Bernhard et al 2006; Madigan et al. 2012).

The dropout rates in the study may have left only the committed participants whereby adherence would be expected to improve, thus reducing the ratings of components effectiveness. This should be considered and future research would benefit from identifying dropouts and reasons why to identify any possible confounding influences.

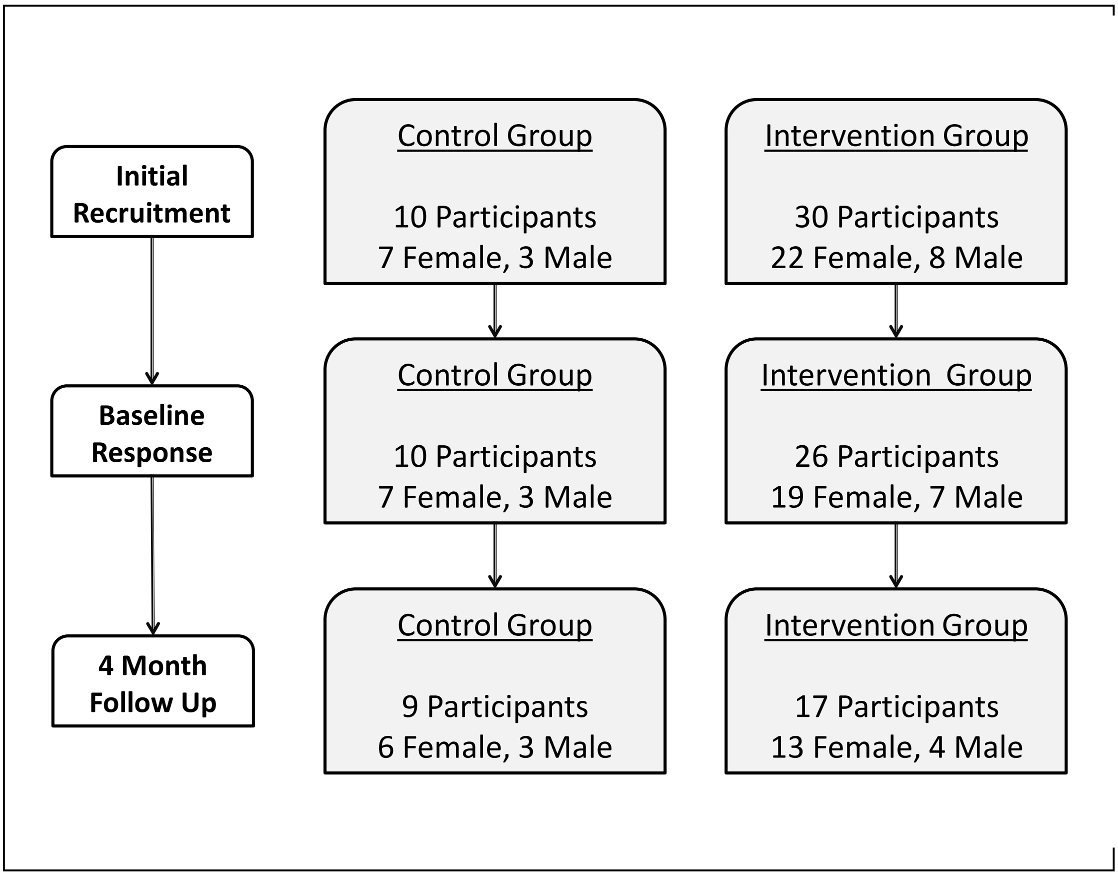


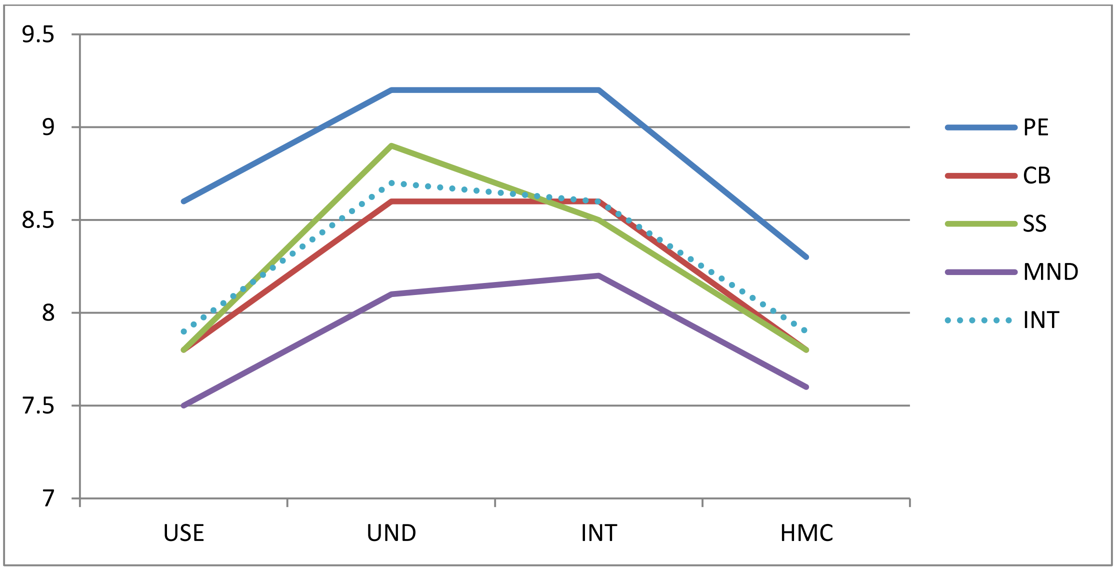
Figure 3.
Shows participants drop out and retention through both control and intervention group.

5.11.2 Acceptability and Meaningfulness

In Table 2 and Graph 1 illustrate the reported scores from the informal caregivers regarding the four intervention components: Usefulness, ease of understanding, interesting, and facilitated change. The psychoeducation component scored the highest in all four categories and the mindfulness component scoring lowest in all categories. The cognitive behavioural and social skills components scored similarly between the other two components with social skills scoring slightly higher in ease of understanding. All components were scored well by participants although the completion percentage rate of each appears to correspond with each component's overall scores.

Intervention Type	Usefulness	Easy to understand	Interesting	Helped to make changes	% Complete
Psychoeducational	8.6	9.2	9.2	8.3	97.9
Cognitive Behavioural	7.8	8.6	8.6	7.8	89.1
Social Skill	7.8	8.9	8.5	7.8	87.4
Mindfulness	7.5	8.1	8.2	7.6	86.2

Table 2: Mean scores from participants regarding usefulness, ease of understanding, interest and extent of helping make changes for each of the four intervention components. All scored 0 (lowest) to 10 (highest). Also includes mean reported completion of each component.



Graph 1: Acceptability and Meaningfulness Scores for all four components and comparison average.

Participants were also given the option of providing any other feedback regarding the intervention:

Comments Regarding Psychoeducational Component

“I had previously not found a one/off, easily understood source of info. to which I could refer whenever I had a query.”
“It has been great to have all the information I need in one place. Before it has been hard to know where to turn to and how to get info.”
“I can still learn something about bipolar disorder after 31 years. Thank you for ‘rapid cycling’ term as seems it is not recognised by GPs and psychiatrists we have met. + made copious notes.”
“Concise. Access to this information early in diagnosis would have been very helpful.”

Comments Regarding Cognitive Behavioural Component

“This part of the intervention did not help me, in my opinion, so much because I did not feel that I had negative thoughts to any great extent in regard to my impact on people.”
“It was really interesting to look at how thinking can change how we act. I have started to notice this more with practice doing it and I can honestly say that I feel better and don’t feel so bad/ down like I used to.”
“Did all the exercises. Some of automatic thoughts made me think what was and wasn’t important to get ‘her up about’ i.e. ‘Standing Back and view the situation’. Made me realise what qualities I had. Improved my self-esteem. Shall do more ‘Automatic Thought’ exercises when feeling low.”
“Useful to add to the coping toolkit.”
“Helped me to stay calm in one or two situations that would normally have upset me.”

Comments Regarding Social Skills Component

“This is the section that has most helped me to improve communication with my son. He is “male” + quiet, I am “female” + very talkative generally!”

“Really made me realise how to talk and how to listen. I was not sure about this to start with as I thought how easy and simple this would be but the way it is explained is not like being talked down do and is clear and useful. Helps when speaking to my husband so I am listening more.”
“Read all this section but didn’t do the exercises. Will try and do them as they appear to be useful.”
“Food for thought. Work in progress.”
“As an SLT communication is part of my life. Unfortunately I’m not a person that reflects a lot rather act on gut feelings. So I was a bit superficial with the exercises. But they ARE good!”

Comments Regarding Mindfulness Component

“I have a “butterfly” brain so the exercises were difficult! I did, however, benefit from realising that I must at times make my own well-being a priority in order to benefit the longer term situation with my son.”
“Taking time out to do this was a big help. The exercises started to get easier and I will definitely keep this up. Really liked it even though it was difficult to start with.”
“Read through and completed reasons why didn’t do mindfulness but not done other “Body Scan” exercise. Completed two “negative thought” exercises in depth. Need to do more. (Find it difficult to do “quiet exercises” due to tinnitus. I relax by walking, gardening and bird watching, doing crosswords and word puzzles. Used to have weekly massages but ‘tinnitus’ overcame the usefulness.”
“Improved quality of life.”
“It encouraged me to “actively” take time off, just concentrating on something nice (and for myself) for a little time. It’s relaxing and gives you new strength.”

Any other comments you would like to make:

“Because my son has been remarkably stable in respect of his Bipolar symptoms for the last 4 months, I probably did not “need” the interventions as much as expected. Your work, however, has provided me with so much knowledge + I intend to keep all the booklets etc for future use. The information section provided a bright light in which had felt like a very dark place. Why don’t hospital staff give relatives any written info. or even website names? When an adult it ill, parents cannot obtain

knowledge RE their treatment without their permission – which our son was reluctant to give when ill. Your interventions have facilitated more open discussion now between us. Joining a carers' support group, through M.H.A, has also helped me recently."
"Thank you very much for doing this research. I have not had support like this before. Little is done for carers of people with mental health lifestyles. If you appear to cope little effort is given to you and people are embarrassed. People "laugh" about activities they see when my husband is hypomanic. People feel free to criticise my husband's "behaviour". I get very defensive, people should not criticise other people. (Only constructively, maybe at work) (I do not criticise other people's husbands) My husband is "bipolar" – is it an "illness"? Is it not part of who he is??? (He had his first hypomanic episode after his father's death 6 years after I met him -> married him) People should be more accepting of people's different personalities. Please contact me if you require any further information (or ramblings). Thank you once again. Best of luck with your research."
"Thank you for allowing access to this information."
"At the moment my bipolar husband and myself are struggling financially after ESA has ended. So all in all our situation lets use feel down. Even my usually cheery self is gone a bit and it reflects in my questionnaire. But we got help = which was a very positive experience. All in all I will keep your booklet and will look at it from time to time as it gives some great hints and surely given ideas to look at the situation in a different way. And that always helps!"
"I have found there is no one coping strategy for dealing with the problems faced by living with a bipolar sufferer. Depending on how I feel at the time, or what the situation is that has arisen, I may adopt different interventions. After years of living with bipolar I sometimes feel I should be able to deal with the problems better than I do, but I'm getting older and have less neutral, emotional and physical stamina that I used to have. Throughout the years I have felt that ne of the best coping strategies and supports would be to have a "buddy" to talk to – someone in a similar position to talk to in times of stress. I have supportive friends and family, as well as a very supportive Carer's Centre where I live, but I don't always want to 'use' our times together 'unloading' my feelings. I haven't found such a "buddy" in all the 26 years but I'm working with my local Carer's Centre in the hope that such a system can be organised in the future. Many years ago I approached the local psychiatric service for support but was advised, in writing, that they were not resourced to deal with carers – only users. This also applies to many mental health support groups who are set up to support users rather than carers. Also, in the past I have attended several training or information events only to discover they were geared towards people working in the profession, or users."

5.11.3 Effectiveness

5.11.3.1 Baseline Analysis

To assess any differences between the intervention and control groups, a between subjects t- test was conducted on each individual outcome measures at baseline: Understanding Mood Disorders Questionnaire (UMDQ), Automatic Thoughts Questionnaire (ATQ), Positive Automatic Thoughts Questionnaire (ATQ-P), Social Support Questionnaire-Short Form (SSQ-6), Five Facet Mindfulness Questionnaire (FFMQ), Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS), Jalowiec Coping Scale (JCS), and Dispositional Resilience Scale – 15 (DRS-15). There were no significant differences between the assessment tool outcomes between the two groups with the exception of the perceived effectives off the subscale of fatalistic coping styles in the JCS; $t(34) = -2.44$, $p = .021$.

The t-test was selected to compare the outcomes of the assessment tools and baseline (before either group accessed the intervention) between the control group and the intervention group. A result that would be significant here in this comparison would indicate that the groups were different at this time in regards to this measurement, i.e, there was a significant difference between the perceived effectiveness of the fatalistic coping styles between those in the control group and those in the intervention group at baseline. None of the other results were significant, i.e. those in the control group and intervention group were not significantly different in any other measured outcome. From this, we can infer that any significant differences between the groups in these seem outcome measures and follow up, can indicate the potential positive benefit of the intervention.

Due to the controlled allocation of group, Chi-Squares were conducted on sociodemographic variables: Job Stats, $\chi(3) = 1.196$, $p = .754$; Highest Educational Level Attained, $\chi(5) = 1.187$, $p = .946$; Relationship to care receiver, $\chi(3)$ 1.156, $p = .764$; Habitation status, $\chi(2) = .533$, $p = .766$; and years since their relative was diagnosed, $\chi(21) = 22.957$, $p = .346$.

These results indicate no significant difference in these variables between the intervention and control group post-allocation.

Comparison between the intervention and control group at baseline showed only one outcome measure to be significantly different between groups: perceived effectiveness of fatalistic coping. The lack of significant difference in the other measures at baseline displays similarity between the groups on the remaining outcome measures and allows for follow up comparison between the groups once the intervention has been administered.

At follow up, any significant differences in UMDQ, ATQ, ATQ-P, SSQ6 and FFMQ refer to assimilation of information from the four intervention components and significant differences in WEMWBS, JCS and DRS-15 refer to overall changes in caregiver health and wellbeing (See figure 2).

5.11.3.2 Longitudinal Follow Up

Repeated measures ANOVAs were conducted for each assessment tool outcome at follow up between the intervention and control group, including separate analysis for subscales where available: UMDQ, SSQ-6, FFMQ, JCS, and DRS-15.

Of the four intervention components, the psychoeducational, cognitive behavioural and mindfulness components showed a significant difference between scores for the intervention and control groups at 4 month follow up. The UMDQ showed assimilation of the psychoeducational component with increased knowledge of mood disorders and symptoms: $F(1,24) = 10.9$, $p < .05$, the ATQ showed assimilation of the cognitive behavioural component with fewer reported negative automatic thoughts: $F(1,24) = 4.39$, $p < .05$, and the FFMQ showed assimilation of the mindfulness component with increased levels of mindfulness: $F(1,24) = 5.90$, $p < .05$. Neither the subjective nor objective subscales of the SSQ-6 showed significant differences between the groups.

Repeated measures ANOVAs were also conducted for the three outcome measures which revealed significant differences between the groups at follow up for wellbeing, with the intervention group showing increased wellbeing, $F(1,24) = 4.33$, $p < .05$, but not in the overall scores for the JCS (coping) or the DRS-15 (resilience). However analysis of subscales revealed significant increase in the resilience subscales for the intervention group regarding commitment, $F(1,23) = 7.0$, $p < .05$, and control, $F(1,23) = 6.32$, $p < .05$, subscales but not the challenge subscale.

Subscale analysis of the JCS was conducted for each of the eight coping styles and the perceived effectiveness of using each coping style. Significant increase was observed in the intervention groups reported use of confrontive, $F(1,24) = 9.88$, $p < .01$, fatalistic, $F(1,24) = 10.27$, $p < .01$, palliative, $F(1,24) = 16.35$, $p < .001$, and self-reliant, $F(1,24) = 10.31$, $p < .01$, coping styles. Also, the perceived effectiveness of the coping styles of the optimistic, $F(1,24) = 5.84$, $p < .05$, emotive, $F(1,24) = 7.24$, $p < .05$, and self-reliant, $F(1,24) = 8.97$, $p < .01$ coping styles, were found to have increased in the intervention group.

Subscale analysis performed on the follow up outcomes between groups showed significant increase in the intervention groups scores for both UMDQ subscales: facts, $F(1, 24) = 10.21$, $p < .01$ and symptoms, $F(1,24) = 5.53$, $p < .05$ and for two of the FFMQ subscales observe, $F(1,24) = 6.40$, $p < .05$ and awareness, $F(1,24) = 7.13$, $p < .05$, and nonreact approaching significance , $F(1,24) = 9.78$, $p = .082$.

Significant results are summarised in Table 3.

Table 3. Summary of all significant differences between control and intervention group at follow up.

Assessment Tool	**Difference in score between intervention and control**	**Implication for intervention group**
Understanding Mood Disorders Questionnaire (UMDQ)	$F(1,24) = 10.9, p < .05$	Increased knowledge of mood disorders in relation to both facts and symptoms.
Understanding Mood Disorders Questionnaire (UMDQ) Facts	$F(1, 24) = 10.21, p < .01$	Increased knowledge of mood disorder facts.
Understanding Mood Disorders Questionnaire (UMDQ) Symptoms	$F(1,24) = 5.53, p < .05$	Increased knowledge of mood disorder symptoms.
Automatic Thoughts Questionnaire (ATQ)	$F(1,24) = 4.39, p < .05$	Decreased occurrence, or recognition, of negative automatic thoughts.
Five Facet Mindfulness Questionnaire (FFMQ)	$F(1,24) = 5.90, p < .05$	Increased engagement of internal stimuli.
Five Facet Mindfulness Questionnaire (FFMQ) Observe	$F(1,24) = 6.40, p < .05$	Increased ability to attend to internal stimuli.
Five Facet Mindfulness Questionnaire (FFMQ) Awareness	$F(1,24) = 7.13, p < .05$	Increased ability maintain focus on internal stimuli.
Jalowiec Coping Scale (JCS) Confrontive	$F(1,24) = 9.88, p < .01$	Increased use of coping regarding constructive problem solving.
Jalowiec Coping Scale (JCS) Fatalistic	$F(1,24) = 10.27, p < .01$	Decreased use of coping regarding pessimistic or hopeless attitude.
Jalowiec Coping Scale (JCS) Palliative	$F(1,24) = 16.35, p < .001$	Decreased use of coping regarding consumption to make oneself feel better.
Jalowiec Coping Scale (JCS) Self-Reliant	$F(1,24) = 10.31, p < .01$	Increased use of coping regarding depending upon oneself rather than others.
Jalowiec Coping Scale (JCS) Perceived effectiveness of Optimistic	$F(1,24) = 5.84, p < .05$	Increased perceived benefit of coping in ways that maintain positive attitudes.
Jalowiec Coping Scale (JCS) Perceived effectiveness of Emotive	$F(1,24) = 7.24, p < .05$	Decreased perceived benefit of coping in ways that express emotion to relieve stress.
Jalowiec Coping Scale (JCS) Perceived effectiveness of Self-Reliant	$F(1,24) = 8.97, p < .01$	Increased perceived benefit of coping in ways that depend on oneself.
Dispositional Resilience Scale (DRS-15) Commitment	$F(1,23) = 7.0, p < .05$	Increased involvement of oneself in activities, with genuine interest in these activities and other people.
Dispositional Resilience Scale (DRS-15) Control	$\mathrm{F}(1,23) = 6.32, p < .05$	Increased belief that one has control over, and can influence life events.
Warwick Edinburgh Mental Wellbeing Scale (WEMWBS)	$F(1,24) = 4.33, p < .05$	Increased level of mental wellbeing.

In summary, the quantitative results revealed perceived acceptability and meaningfulness of the four components of the intervention. Significant differences in the outcome measures and follow up indicate positive potential for these components.

5.12 Chapter Summary

Significant differences between the intervention and control group at follow up were seen in the UMDQ, ATQ and facets of the FFMQ. These assessment tools measured the outcomes that would be affected by interaction with the psychoeducational, cognitive behavioural and mindfulness intervention components. The SSQ-6, the equivalent assessment tool for the social skills intervention component, did not show significant change between the groups at follow up. Wellbeing, positive coping styles and facets of resilience showed a significant increase with the WEMWBS, JCS and DRS-15 respectively. The combined qualitative and quantitative results are discussed in Chapter 6.

Chapter Six: Discussion

6.1 Introduction

This chapter provides a discussion of the combined results of Stages One and Stage Three of the research study reported in the thesis. First, the purpose of the study is briefly stated, and a summarised framework that was adopted to help accomplish the research. Included in the discussion of the results for both the qualitative and quantitative components are supporting evidence and references from appropriate literature. How the results from the study contributes to what is already known about the topic, implications for practice, policy, suggestions for future research, and recommendations are identified, and presented in Chapter 7 under conclusions.

6.2 Presentation of Discussion

The purpose of this sequential exploratory mixed methods research was to explore the lived experiences of caregivers of persons with BD, to create and pilot a multiple component intervention to increase health and wellbeing.

The major themes from Stage One (qualitative) are discussed in the same order as they were presented in Chapter 5. Stage Three results (quantitative) are discussed with reference to feasibility, acceptability and meaningfulness, and effectiveness of the intervention developed and piloted.

6.3 Provision of Care

Informal caregivers as a general population provide a plethora of support to their relative ranging from personal care, assistance with activities of daily living to emotional support (Dooghe 1992). However, in regards to the caregivers of persons with mental health conditions, this provision of support can skew to less physical means of support as seen in older adult and palliative care, and include higher rates of emotional and psychological support (Jegermalm 2006). Typologies of care provision from informal caregivers arose to identify the ‘degree’ or ‘level’ of care provided in an effort to quantify a caring spectrum (Parker and Lawton 1994). Such efforts hoped to identify the caregivers most at need through higher levels of support provision. These analyses were critiqued by Nolan, Grant and Keady (1996) to rely upon instrumental models of caring that overlooked the multifaceted components of the experience, and only relied upon physical dimensions of the role. The association between objective and subjective burdens have also been reported inconsistently (Jones 1996).

Such identifications of the diversity of the role and how it can be experienced led to the value of the objective and subjective distinction of burden in caregiving (Hoffmann and Mitchell 1998). Objective burden would arise from caregiver appraisal of situations and subjective burden would arise from their appraisal of care recipient behaviours (Jones, 1996). However, the utility of this dichotomy was challenged by Montgomery (1996) where the author stated "*there is no single, generic caregiver role; rather, caregiving is a role that emerges from prior role relationships and is influenced by values, beliefs, and life circumstances of an individual caregiver*" (p. S109) and Ogilvie, Morant and Goodwin (2005) who suggested that the two may be less distinct than they appear and are treated to be. These authors suggest that the role itself is dynamic over time and cannot be predicted from duties and tasks observed but rather that the experiences of the caregivers; their views, perceptions and feelings were how we could truly come to understand their experiences.

Therefore, the identified provisions of care from the interviews in the study reported in this thesis are not an exhaustive list of support provided by the caregivers, but rather the tasks and duties that they mentioned the most as important or impacting on them in some way. The focus of the interviews were not aimed to create a rigid typology of care provided but rather to follow the ideologies of Gadamer and Heidegger in that the caregivers' experiences were of optimal importance. The information provided is still useful especially in regards to engagement with the hermeneutic circle by facilitating a fusion of horizons with context for the experiences relayed by the participants.

6.3.1 Assisting Basic Functioning

The most reported form of provision of care, related to assisting with basic functioning and the fulfilment of activities of daily living (Katz et al*.* 1963). Such support is documented and diverse, especially in relation to caregivers for relatives with BD, and the dynamic nature of symptoms and consequential behaviour can result in a vast and changing array of the care recipient's need (Rusner et al. 2012; Rusner et al. 2013). This diversity was reflected by the participants as both the effects of depression and mania required specified responses from the caregivers such as the instigation of daily routines when care recipients were low in mood and to direct attentions when their moods were high.

Assistance with basic functioning required a great deal of time and effort for the caregivers as they had to not only organise and look after themselves but also their relative. Continuous and overwhelming provision of such support has been shown to limit the caregivers' ability to focus on their own future which leads to a lack of personal identity (Jönsson et al*.* 2011). Caregivers require a personal identity, as does anyone, for the sake of self-esteem and self-efficacy (Talley and Montgomery 2013). An impairment of these can lead to psychological effects which can impact negatively on the caregiving role, the caregiver and the care recipient (Heine 1999; Shapiro, Brown and Biegel 2007).

6.3.2 Emotional Support

When relatives required it, the participants provided emotional support. They provided encouragement, stability and someone they could talk to. Support seeking behaviour in a relationship arises when one experiences a stressful or threatening situation (Collins and Feeney 2000). This is emulated by the participants' relatives seeking affirmation and comfort. The familiarity of caregivers and their care recipients may affect the ways in which they interact in emotion support seeking, in comparison to professional support providers, and should be considered for further study to better understand the differences in care provided by the two groups.

6.3.3 Adherence to Treatment

Beyond basic functioning, a high reporting of ensuring care recipient adherence to treatment plans arose. This included making appointments with mental health care professionals for their relative and in some cases taking them to, and accompanying them at, appointments, whilst ensuring adherence to medication regimes. The care recipients are exponentially more likely to reach adequate levels of recovery and experience fewer mood disturbances if adhering to treatment plans and meeting regularly with healthcare professionals (Nathan and Gorman 2002), and it would appear that informal caregivers play an integral role in this. It is possible that without the support and encouragement from their carers that the care recipients may not involve themselves as routinely with their mental health care regimes, and not improve to the same extent (Deekan et al*.* 2003).

However, it can be argued that this more apathetic approach to medication regimes and planning appointments could be as a result of the caregivers being overly involved and relinquishing control from the care recipient (Eisner and Johnson 2008). Studies of caregivers with high levels of expressed emotion (EE) (Tattan and Tarrier 2000; Eisner and Johnson 2008; Grice et al. 2009) could support this possibility. EE relates to caregivers displaying a high level of critical or hostile attitudes or become overly emotionally involved with their relative. Were a caregiver displays high levels of EE, they would be inclined to take control of treatment adherence. Nonetheless, , considering that informal caregivers can evoke higher levels of recovery and psychosocial functioning compared to a professional caring alternative, improved outcome is not representative of behaviours of high EE caregivers.

6.3.4 Familial Support

The care requirements arising from caring for a relative extended beyond the care recipient personally into providing support for those of whom would have been supported, or had been supported by their now care receiving relative, who could no longer do so due to illness. The participants provided a majority of childcare for their own children if their relative was their spouse and for their grandchildren when their relative was their own child. It was recognised by the carers that these were not people that they would not care for if their care recipient was well, but that they were involved to a greater degree which was recognised to create a different parent-child/ grandparent-grandchild dynamic.

Literature linked to the changing nature of marital and sexual satisfaction in spousal caregivers (Lam et al*.* 2005), whereby relationship dynamics such as responsiveness and displayed affection can be influenced due to changes in mood states. However, it is also important to understand the relationship with other family members who receive disproportionate and/or dynamically different care from the caregiver of the relative with BD. Especially when the caregiver/care receiver relationship is in its infancy, it is important for the carer to develop an identity, and for this identity to operate congruently with the care receiver to minimise strain (Coeling, Biordi and Theis 2004). All relationships should be recognised, especially with those of whom receive this familial support, as a reported dynamic change in these relationships could impact upon the identity of the carer, or assistance in recognising these differences may also facilitate this response.

6.3.5 Financial Support

The provision of financial care, such as paying for or assisting in the paying of necessary items or providing goods of monetary value, is not generally directly reported following analysis for caregivers of persons with BD, but is mentioned generally as a form of burden or strain (Deekan et al. 2003; Goodwin and Jamison 2007; Maskill et al*.* 2010). However, Wolff et al. (2006) undertook a study of 486 primary caregivers of relatives with BD to model an estimate of their financial implications. Following semi-structured interviews that assessed the types of support provided, use of formal and informal services by both the care receiver and care recipient, caregiver perceived distress, and contributions of the care recipient; the authors concluded that caregivers did not view the entirety of what they provided to constitute care, but rather what they perceived to be having to provide, because they were caring for their relative.

Participants reported having to provide financial support as a consequence of manic mood phases and also through the loss of a household wage as their relative were unable to work. Wolff et al. (2006) reported how even with something as intrinsic as money, caregivers tend not to perceive strain or burden in relation to quantifiable means, but rather based on their own interpretations and judgements of situations. The components of care provision can therefore be understood, at least in part, to be constituted by the beliefs and perceptions of the caregivers. Quantifying these aspects could lead to limited understandings of the role and experiences of caregivers. The feeling of being on call is a good example of this.

6.3.6 Being on Call

Being on call, referred to the unerring responsiveness of caring for their relative. The participants found it hard to state exactly what periods of time these referred to and instead opted to say that it was a constant phenomenon. Feelings of guilt and anxiety were elicited within the caregivers when they were not with their care recipient, and/or did not know what they were presently undertaking. This compelling feeling seemed not to be directly attributable to mood states or external stimuli and continued to affect the carers even when their relatives were relatively well. This supports research to suggest that stages of 'wellness' encountered during a euthymic stage of a relative does not leave the carer unburdened or unstrained as was previously thought (Lefley 2010).

The caregivers' experiences of being on call are congruent with this belief, and it is possible that this state of constant obligation arises through a continual monitoring of their relatives moods, risk signs and general welfare for their relative. Frequently discerning these signs with emotional and cognitive hypervigilance (Chambers, Ryan and Connor 2001; Rusner et al. 2012) could lead to increased levels of anxiety as the caregivers are pre-mediating worst possible scenarios, and experiencing the psychological implications of such a mind-set (Curwen, Palmer and Ruddell 2008). However, research has shown neurocognitive impairments in people with BD whilst in the euthymic state impairing psychomotor skills, attention, decision making and memory (Thompson et al*.* 2005), which could contribute towards the notion of continual care attention on behalf of the carers.

6.4 Caregiver knowledge of Bipolar Disorder

It has been recognised that it can be difficult for caregivers to live with uncertainty regarding the course, prognosis and treatment of their care receivers (Rose 1999), and that lack of caregiver understanding of BD and its symptoms can lead to substantial impact on the psychosocial wellbeing of the carer (Perlick 1999). Such lack of awareness of their care recipient's condition has also been shown to lead to reduced use of social support, i.e. reaching out and talking to friends or family (Chakrabarti and Gill 2002).

The knowledge and understanding of BD by the participants in the study was mixed and generally derived from personal experience with their relative, which would suggest that those new to the role would have higher knowledge needs to avoid negative effect. Conversely this also suggests that the care givers have the capacity to learn through their experiences and that they may, in time, at least partially avoid the negative consequences of unfamiliarity with BD. Increased understanding of care recipient condition has been shown to produced increased positive family interactions, decreased family burden and reduced relapse rates for the relatives (Eisner and Johnson 2008; Lobban et al*.* 2013), and can even improve such outcomes from as early as the first episode of care recipient psychosis (McWilliams et al*.* 2010).

A rather crucial facet of caregiver understanding arose with the knowledge of the nature of BD in that it was chronic and therefore only treatable rather than curable. Recognising this aspect of BD appeared to facilitate acceptance of their role as caregivers by removing possible ambiguity or false hope around the notion of complete recovery for their relatives. Acceptance in caregivers can play an important role in both psychosocial and health outcomes for themselves and their care recipients, as awareness of the severity of BD can allow caregivers the opportunity to understand and feel in control (Perlick et al*.* 1999). Such adaption can be considered a style of coping and is discussed further under section 6.7 in this chapter.

The caregivers also reported difficulty in both sourcing and validating information on BD. All participants had attempted to learn more about the condition and had either limited success or none at all, in their opinions. This indicates that the desire to learn more by caregivers could be met by providing easily accessible information through a source that caregivers can trust to be authentic. Caregivers for relatives with mental health conditions have also expressed their views that inadequate reliable information resources are available to them (Kerr et al*.* 2006; Drapalski et al*.* 2008).

Changing or altering caring practice based on information that the carers could not trust was unlikely as the outcome for poor decision or misdirection would lead to the detriment of the very person they cared for. Despite feeling like they did not possess the resources to learn more, the caregivers had made observations based on their relatives and had made sense of BD in this way. The need for individualised approaches to the satiation of knowledge needs is accepted through the acknowledgement that *"every member of every family is an individual and has varying information needs."* (Rose 1999 p.82). However, it is recognised that caregivers for relatives with BD are unsupported in regards to provision of accessible evidence-based information (Berk et al. 2013).

6.5 Positive aspects of the role

As stated earlier, to fully understand lived experience, it is necessary not to limit the scope of investigation and remain as open and neutral as possible (Annells 1996). Such a whole state approach began to emerge in caregiver research as consideration for the positive aspects of the role emerged. Researchers identified that alongside the well reported aspects of carer strain, carer burden and carer needs, that a relatively unreported component of the caring role remained: positive aspects (Brouwer et al*.* 2005). Akin to Antonovsky's salutogenic considerations of healthcare (1979) where the focus of health relates to factors that maintain health rather than those detriment to it, the aspects of the role that kept caregivers well rather than what impacted upon them negatively, could reveal explanations for how and why relative carers managed despite consistent findings of impaired psychosocial outcomes (Simoneau et al*.* 1999; Perlick et al. 2007; Steele, Maruyama and Glaynker, 2010).

Wennerberg, Lundgren and Danielson (2012) explored these positive aspects through guided interviews with thirty two caregivers of older adults. They were concerned with the prevalence and use of General Resistance Resources (GRRs): referring to inherent capabilities and characteristics possessed by individuals or groups that aide the management of tension or reactions to stress (Antonovsky, 1985; Langeland et al*.* 2007). The authors' coin a term called *Cargivinghood* to personify their findings which resulted from an analytical process of moving between qualitative and quantitative outcomes from their interviews. The authors note that participants could find it difficult to identify positive components, but an earlier study by Cohen, Colantonio and Vernich (2002) reported that 73% of 289 caregivers were able to identify at least one positive aspect specific to their role. This may suggest that the particular research methodology adopted by Wennerberg *et al.* may not have been as appropriate to explore such a concept and in regards to a phenomenological standpoint, would have been unable to fully explore the richness of lived experiences through paradigm bias and objectivity (Moran and Mooney 2002).

Positive outcomes have been identified across studies relating to those caring for the elderly (Lawton et al. 1992), chronic illness (Hunt 2003) and those with mental health conditions (Brouwer et al*.* 2005), reflecting that positive outcome is not limited to one particular subset or typology of informal caregiver. Understanding the perceived positive aspects of the informal caregiving role is necessary to fully understand how the caregivers regard their lives and experiences as without this understanding, we would be limited to the negative aspects only and this would be misrepresentative. Of the four positive outcomes elucidated from the interviews, the most prominently reported in other papers was that of 'Meaning through caregiving' (Nolan et al. 2004).

6.5.1 Meaning through Caregiving

Meaning through caregiving refers to an internal process of reflection on behalf of the caregiver that resulted in denoting positive affect to their role. Meaning through caregiving may be a prerequisite to appreciating the possibility of positive outcomes in the informal caregiving role and has been shown to increase levels of caregiver satisfaction and confidence (Hunt 2003). In this way, the capacity of appreciating meaning through caregiving in itself allows for greater development of potential self-enhancing mentalities and personifies the importance of exploring and understanding these aspects of the role. Such appreciations on behalf of the participants in this study recognised a closeness with their care receiver, that would not otherwise have come to be. They did not refer to this as what they would have wanted but nonetheless recognised that, a dynamic of supporting and fulfilling their relative's needs resulted in positive feelings.

The potential benefits in the caregiving role have sometimes been referred to as 'uplifts' and are referred to as '*small events that evoke some response of pleasure, affirmation, or joy'* (Lawton et al. 1989, p. 62) and are thought to be intrinsic in caregiving relationships which is enforced through the higher incidence of uplifts experienced by caregivers deemed to be more 'involved' (Kinney and Stephens, 1989). If such an inherent component of the caregiving role exists, it is essential to understand the processes behind it to ensure that such measures are maintained and enhanced to elicit the positive effects that it is capable of.

6.5.2 Quality Care for the Care Receiver

The caregivers also reported that they recognised that their efforts culminated in a high degree of quality care for their relative, the quality of which may not have been met had it not been for their own efforts and actions. In recognising the benefits of their actions, it can be argued that the caregivers could take positive effect from knowing they had done their jobs well and therefore done well by their relatives. Brouwer et al (2005) defined this acknowledgement through the term *process utility* which referred to '*the difference in happiness between the current situation in which the care recipient is cared for by the caregiver, and the hypothetical situation that someone else takes over the care tasks, all other things equal*.' (p. 85). The authors found that almost half of the nine-hundred-and-fifty caregivers procured process utility from their role, and that average happiness would be reduced if the caregiving role were to be relinquished to this hypothetical caregiver.

These high rates of self-reported process utility indicate that such positive influences greatly impact on the caregiver's perception of their role. By declining the hypothetical situation in which they could withdraw as caregiver in place of another suggests that, the role itself is perceived as significant. The impetus for caregivers to do what they do despite the negative effects of the role, further display the importance of a whole state approach to understanding lived experiences, for such substantial components would otherwise go unnoticed and unreported. In the efforts of supporting caregivers, understanding exactly *why* they provide the on-going service they do is of great importance especially in regards to those of whom are new to the caring role, when they may be more vulnerable and in need of encouragement and assistance than those more experienced and accustomed to the role (Tennakoon et al*.* 2000; Cohen, Colantonio and Vernich 2002).

6.5.3 Personal Growth or Change

The caregivers that participated in the interviews were experienced in providing care and it may be through their adaptions to the role and their experiences ,that allowed them the clarity and hindsight by which to perceive and acknowledge such positive aspects, but one positive facet ‘Personal Growth or Change’ is indeed routed in experience. Personal Change can be described as the internal and insightful process whereby an individual develops talents and capabilities in response to both external and internal stimuli (Leipold, Schacke and Zank 2008), and was recognised to have occurred over time as the caregivers changed as a person to better suit the role they were expected to fulfil.

It is estimated that between 55 and 90% of caregivers experience personal growth in response to their role (Ott et al*.* 2007) and this estimate seems justified by the claim of Hogan and Schmidt (2002) who stated that personal growth can develop and materialise following difficult life events, which the caregivers are evidently experiencing. In this sense, personal growth can be understood as a responsive phenomenon to negative life events and borderlines an automatic coping response by the carers.

Maskill et al*.* (2010) interviewed caregivers of relatives with BD and one of the two sub-themes reported was “I am a much more compassionate person.” referencing a recognition of personal growth, which juxtaposed the other sub -theme of “It’s tough and it’s a sacrifice.” This dichotomy was personified as ‘Two sides of the same coin.’ to reflect the distinct but interacting positive and negative aspects of the role. Reporting of such self-identity development in the intercept population for this study enforces the notion that a whole state approach to lived experience is truly necessary as those caring for relatives with BD, like other caregivers of people with other conditions and illnesses have the capacity of perceiving both the negative and positive aspects of their experiences.

Further understanding of how and when personal growth develops and becomes actualised is required to instil such fortitude in carers to assist in protecting themselves from the negative consequences. Conversely, due to the responsive nature of personal growth, an alleviation of negative effects may also decrease the caregivers’ capacity for personal growth to develop. From a utilitarian standpoint this may appear clearly as a good thing but without fully negating the negative aspects of the role, decreasing the caregivers’ abilities to adapt and grow may occur consequentially through intervention assistance and should therefore be monitored. Kunzler et al. (2014) investigated both personal and dyadic growth in couples coping with cancer and found that as the personal growth of female carers increased, their male care receiver’s capacity for personal growth decreased. This dynamic of personal growth and change displays how delicate a balance such a facet of the caring role can be and that it must be treated with a respectful care when intervening in the lives of caregivers and their relatives.

6.5.4 Recognising Strength of the Care Receiver

The final positive theme elucidated from the transcribed interviews is recognition of strength of the care receiver. The caregivers displayed a capacity to empathise with what their relative was going through and having experienced them trying to cope and manage they were able to perceive aspects of their character such as determination, commitment and courage that they may not have otherwise witnessed. Being in a position to have experienced these character traits and to possess the capacity to empathise with what their care receiver has, and is, going through may be subject to experience also. The ability to understand their relative’s experiences is not likely to be a skill that is inherently strong from the beginning, as a true and deep empathy requires effort and the affiliation to develop (Martire 2005).

6.5.5 Conclusion

The four positive aspects of the role appear to hinge on the passing of time and experience. This indicates that the caregiving role involves an accrual of skills over time in relation to the role and what it entails. These positive aspects are highly associated with healthier psychosocial outcomes and appear to develop across time. Those new to the caregiving role are less likely to experience these benefits, and the means through which they accrue should be further investigated to facilitate their induction and conservation. If experienced caregivers have developed and realised such positive aspects through practice, resourcefulness, and involvement, it is evident that progress in to understanding how best to provide assistance to those who care for a relative may be rooted in the capabilities of those veteran to the role.

6.6 Negative Aspects of the Role

Of the negative aspects of the role, the most prominently reported by the caregivers was dealing with challenging behaviour from their care recipient. As Barrowclough and Parle (1996) recognised, caregivers tend to react to the specific illness symptoms rather than to the diagnosis itself and Perlick *et al*. (1999) found that 91% of the BD caregivers in their study reported burden arising from coping with care receiver behaviours. Challenging behaviours were dependent on the mood states of their care receivers with the expected increases in irritability, irrationality and high paced actions associated with mania, and the withdrawn and depressed behaviours, and suicidal propensity more common with depressed mood states (Merikangas et al*.* 2011; Swann 2013).

6.6.1 Dealing with Challenging Behaviour

In 2006, Reinares et al*.* interviewed from the same population and found highest rates of self-reported distress linked to the behaviour of their patient. Also, the adverse aspect of the negative/positive dichotomy of lived experiences of BD caregivers, 'It's tough and it's a sacrifice.' was speculated to be in relation to dealing with the behaviours arising from BD (Maskill 2010). Evidently, the caregiver role for a person with BD has dealings with behaviours rooted as the cornerstone of negative caregiving experiences. This is not overly unexpected however, considering the contact and exposure of these behaviours are both chronic and fluctuable (Swann 2013), and are reported in caregivers of older adults (Chambers, Ryan and Connor 2001), and mental health generally (Barrowclough and Parle 1996; Dyck, Short and Vitaliano 1999), indicating a universality and severity of dealing with behaviours.

Research has, however, shown that caregiver perception of behaviours can impact on the levels of experienced burden and alleviate negative psychosocial consequences due to the forming of dissociation between care receiver and illness leading to decreased perceived intentionality of behaviours (Barrowclough and Tarrier 1992; Gerdener, Buckwalter and Reed 2002). Such discernment is related to an increase in caregiver health but is markedly more difficult to instigate and teach management of through self-care due to the absence of interpersonal dynamics compared to the alternate therapist-led interventions (Ruwaard et al. 1999). It would therefore seem that a deeper understanding of the challenging behaviours would be beneficial with reference to caregiver health and the relationship between caregiver and care receiver.

From the participants interviewed in this study, the most difficult behaviour to understand was that of suicidal propensity and ideation, replicating the high psychological distress of caregivers in relation to such behaviours (Chessick et al*.* 2007; Shah, Wadoo and Latoo 2010). The caregivers were unable to comprehend the mind-set of their care receivers when behaving and acting in this way despite their displayed abilities of empathy, understanding and appreciation from the positive aspects of the role. It would stand to reason that a deeper understanding of these behaviours could benefit the caregiver in their perceptions of, and consequential dealings with care receiver actions deemed challenging. Caregivers who are unaware of their relative's illness are less likely to use adaptive strategies to cope and are at higher risk of detriment than those who do (Chakrabarti and Gill 2002).

Contrary to this Perlick et al. (2007) reported increased burden in BD caregivers when made aware of the severity of their relatives' illness. The authors postulate that this was due to a lack of perceived control and helplessness at being made aware of the magnitude of their role. While this may be a possible influence of intervention assistance, many authors agree the benefits of confidence and competence at dealing with care receiver behaviours result in the reduction of negative effects of the role, and this consequential increase in burden is related to personal awareness of the problems faced by caregivers (Barrowclough and Parle 1996; Ducharme et al*.* 2011; Wrosch, Ella and Miller 2011; Berk et al*.* 2013).

6.6.2 Loss of Identity

The caregivers had noticed that the person they perceived themselves to be was different to whom they had previously believed. In accommodating the role of informal caregiver, they had had to sacrifice aspects of their own life to allow congruence with a new way of life. Ogilvie, Morant and Goodwin (2005) denote this well:

> *'Burden is also related to the development and nature of a person's self-identity in their role as caregiver. Most people who view themselves as informal caregivers have experience an important transition in which the relationship of 'carer-cared for' has superimposed on the existing spousal , family, or friendship relationship.'* (p. 27)

The very act of caring requires a person to accept the responsibilities and duties required of that role and when these conflict with the personal wants and desires of the person, they have the choice of self-fulfilment, putting one's needs first, and self-effacement, prioritising the needs of others (Van der Voort et al*.* 2009). Higher and disproportionate rates of self-effacement lead to increased burden and decreased marital satisfaction when the care giver and receiver are spouses (Lam et al*.* 2005; Van der Voort et al*.* 2009). If caregivers have low concern for self-fulfilment in lieu of focus for the health and wellbeing of their caregiver, their own disregard for their own self and wellbeing may be at the root of the reported loss of identity. A loss of identity can arise when we compare our current situation to previous ones, whereby we feel things have changed so much that we no longer have a frame of reference for understanding who we are (Thoits 2013). This is not isolated to caring but exists regarding a 'way of life' as loss of identity has even been reported following the loss of a home (Dugan 2007).

If high levels of self-effacement can increase caregiver burden and impact on self-identity, increasing caregiver behaviours towards self-fulfilment should prove prudent in maintaining self-identity. The opportunity for caregivers to have their own focus, goals or personal focus to enhance these levels of self-fulfilment and intervention work with caregivers should include this, to ensure these needs are met. Caring for a relative should not encompass a person and if care needs exceed this fulfilment-effacement balance, external support should be offered to ensure that this equilibrium of providing care and looking after oneself is maintained.

6.6.3 Caregiving Concerns

Caregiving concerns embody the worries and doubts expressed by the caregivers of their role. These tended to concentrate on apprehensions of what their care recipient was doing if they were not with them, and what they *would* do if they were no longer able to provide care for them. The caregivers saw themselves as an integral aspect of the safety, and aforementioned quality of care, for their care receiver and this encumbers them to fear the loss of their valuable service and the consequences of this. From the participants interviewed in this study, those who reported the fear of what would happen to their relative in their absence were parent caregivers and the eldest of the spousal caregivers which could suggest that, these worries increase with age, as increased awareness of one's own finitude and mortality are associated with age (Kotter-Grühn, Grühn and Smith 2010).

Rose (2006) also found that caregivers worried most about who would look after their relative if they were no longer able and doubted that such provision of care could be given. This would indicate that the caregivers who are older or more mindful of their finitude may be more inclined to worry and would require greater assistance regarding this. Putting contingency plans in place with caregivers could possibly ease this concern. Increased social support has also been found to decrease pessimistic views of the future (Magliano et al 2004), however extended family does not always have this positive influence, as such support is perceived in benefit, by congruence in approach, and beliefs regarding mental health.

The other concern that predominated the caregivers' interviews was that of wanting to know where their relative was and feeling uneasy if they did not know this. Concern arose with the care receiver behaviours that could be self-harming or destructive, and feeling unable to determine when these behaviours would arise, the caregivers worried about when and if they would. Further understanding of behaviours and triggers may be of assistance to enabling caregivers to feel more informed about the possibilities of such behaviour and utilise this information in coping.

Both of these concerns are related to possible futures and create anxiety through premeditations of potential outcomes. This catastrophic prophesising leads to increased levels of stress, anxiety and strain that will continue to exist, as these feared outcomes are constantly upheld against the passing of time as 'something that might happen' (Vowles 2013). The latter of these concerns regarding care receiver health in their absence seemed to foreshadow the next theme.

6.6.4 Being Bound to the Care Receiver

The caregivers faced a dilemma of providing care relating to the previously discussed self-fulfilment/effacement issue. Being there for their loved one allowed them to provide the high standard of care that they felt their relative deserved but with that came the overarching effects of strain and burden. These consequences left the caregivers requiring their own time for solace and relaxation, but this time of self-fulfilment was met with anxieties regarding the welfare of their relative in their absence. Either of these choices leads to less than desirable health outcomes for the caregivers, and a method of instilling a sense of own space and personal fulfilment without the interfering effects of being bound to the care recipient, appear to be an essential component of improving the lives of informal caregivers.

Being Bound represents a 'catch twenty-two' effect of caring for their relative to their own detriment, and feeling unable to take time away from the role to recover. The guilt and anxiety caused by not being with their care receiver to ensure their personal safety and standards of care are the barriers that seem to hold the caregivers back from taking time to look after themselves.

In the phenomenological study by Rusner et al. (2012) under the broad theme Struggling for Survival, where a participant described *'…feeling guilt for not spending time with her* [care receiver]…' (p. 203) is the closest reference to this in the current caregiving research. The three themes in the study seem rich with data but the experiences are hidden within broad themes. Had the study adopted a more hermeneutic approach that accepted bracketing, this theme may have been described sooner.

When both being with and being without the contact of their care receiver elicit negative effect, being 'bound' should be investigated in greater depth to uncover the processes behind this phenomena so that it can be controlled and the effects alleviated.

6.7 Perspectives of Life Changes

Becoming and being a caregiver for a relative clearly impacted upon the lives of the participants and in all the aspects of their lives, having required changes through the provision of support and the demands therein. The reported life changes were specific points in time that the caregivers mentioned explicitly and were recalled with depth and clarity. The most prominent of these was the point at which their relative was given their diagnosis of BD. The caregivers' experiences of this particular point in time were influenced by the time separating their relative becoming observably unwell, and the point of diagnosis. Where illness onset and diagnosis were close, the experiences of the caregivers took a markedly different perspective from those who had experienced their relative as living with a condition for a time prior to diagnosis.

6.7.1 Care Recipient Diagnosis

The point of diagnosis was experienced far more negatively by the caregivers whose relative had not been unwell for quite long prior to this point, i.e. shorter duration of absence prior to receiving a diagnosis. The participants perceived the diagnosis as a point in their experiences where they were overcome with doubt, shock and loss. These feelings emerged from feeling that diagnosis signalled the ending of their previous way of life, or at least their perceptions of how things would now be instead. Recalling that they were overwhelmed and unsure what to do, the participants recognised this time to be an area of need regarding support and assistance.

Goossens et al*.* (2011) recognised the impact that diagnosis could have on caregivers considering the lifelong condition that their relative had which would result in numerous consequences and significant life changes. The hospitalisation of a relative can also increase the burden of caregivers of persons with BD (Perlick et al*.* 1999), so receiving diagnosis at the point of a first episode and hospitalisation has the potential to amplify the effects of such negative experiences.

Where diagnosis and the relatives' illness onset were separated, the caregivers interestingly experienced diagnosis in a less negative way. Essentially having already been experiencing the caregiving role and the challenges it engenders, receiving a diagnosis was seen to be answering questions about what had been going on, and identified the challenges they had been facing. Lam et al*.* (2005) reported that 34 out of 37 caregivers reported that they were still happy to live with their care receiver following diagnosis, of course, being 'happy' to still live with someone does not guarantee positive experiences of the caregiving role but shows an optimistic outlook of the caregivers post-diagnosis.

Having lived with a relative with a mental health condition for longer those who experienced diagnosis later had a propensity to focus on the help that their relative received, and the observable changes that occurred in their relatives. This shift in focus sounds like a more positive experience in comparison, to those of whom experienced illness onset and diagnosis closer. And potentially these caregivers had gone through similar processes but at an earlier time as they watched their relatives behaviour change and experienced them becoming ill. Not having a label or a name for what their relative was facing may have altered the caregivers' experiences, but it should be recognised that, a similarly consequential exposure may last longer with lesser intensity likely.

This contrast of perceptions regarding diagnosis should be further investigated to ascertain the turning point in opinion when a caregiver perceives diagnosis as beneficial, as the perceptions of how a person views their role in caring for a relative can greatly impact on their health (Shaw et al*.* 2013). Both aforementioned desires reflect care needs of the participants for emotional support and someone to explain the possible outcomes of diagnosis with them. The outcomes are also pertinent to those who are caring but for a relative who does not have a diagnosis, for they too, evidently, appear to require support in dealing with the consequences of mental health that they are unable to fully comprehend without identification of the condition.

6.7.2 Disruption to the Future

Due to the chronic nature of BD, the caregivers found that the plans they had had for their lives and their family had been changed and even lost. Feelings of lost potential has been reported in BD caregivers (Maskill et al*.* 2010), where caregivers have experienced a sense of loss or grief for their idealised potential future that no longer seems attainable due to the consequences of their relatives illness. These disruptions to the future occur due to their relative no longer being able to do the things they used to because of the consequences of their illness, and also from the caregivers no longer having the resources or opportunities to fulfil their pre-empted ideals of the future. Rose, Mallinson and Walton-Moss (2002) reported that the caregiver is first met with the ambiguity of a diagnosis which is shortly followed by the longer process of dealing with outcomes of their relative’s illness, whilst containing losses, and that it is only at this point where perceptions can shift to match the newly confronted reality of being a caregiver. The authors recognised that this stage of acceptance and perception change is where re-affirmations of hope, relationships, stability and achieving a sought after ‘normality’ can flourish.

Finding their plans and ambitions limited, if not lost, could greatly impact on the self-identity of the caregivers as they would be restricted in their own self-oriented endeavours, and have to place a greater impetus on the more present concerns for their care recipient (Thoits 2013). Further investigation in to the potential revival, or adaptive reconstruction, of these lost desires and ambitions should be undertaken to investigate the extent of how these disrupted futures impact on the health and wellbeing of the caregivers. Considering that disruption of future plans would affect the aforementioned self-effacement/ fulfilment dilemma, and impact on caregiver identity (Rusner et al. 2012), improving and controlling this facet of the role could potentially improve these areas and consequently improve the psychosocial outcomes associated with them.

This finding also relates to one of the themes found by Champlin (2009) with caregivers of persons with mental health conditions. The theme was entitled 'Accepting the changed other and grieving the loss of who the other once was'. Acceptance and loss partly reflect the nature of 'Disruption to the Future' whereby the caregivers had to come to terms with their relative now being different and somewhat changed following illness onset and the mourning for the plans and ambitions of the future that could no longer be. To help caregivers overcome this loss, explanation, and discussion of restructured possibilities could assist in the reformation of studied disrupted futures in caregiver and intervention development research.

6.8 Coping Styles

The way in which people cope, i.e. coping styles, mechanisms, processes and strategies, can be understood as cognitive and behavioural adaptive outcomes, manifested in response to external and/or internal challenges that are appraised to challenge or exceed a person's perceived abilities and resources (Lazarus and Folkman 1984; Brown et al*.* 1995; Mackay and Pakenham 2012). These responsive coping processes serve to manage a person's perceived relationship with their environment and to regulate emotions that are perceived as stressful (Chambers, Ryan and Connor 2001). Those caring for a relative with a mental health condition report higher levels of stress than the general population (Van Wijngaarden et al. 2004), and those of this subset who care for a relative with BD experience episodic and unpredictable behaviours which also have been shown to further increase levels of perceived stress (Schulze and Rossler 2005).

Coping styles can vary depending on personal experience, training and personality types (Heim, 1995) but overall, those caring for a relative with a mental health condition do not differ significantly in their coping styles than the general public (Ösman and Hannson 2001). Low caregiver satisfaction with their coping styles is a predictor of low burden (Solomon and Draine 1995) and belief in these skills have been shown to positively impact on psychosocial outcomes (Perlick et al. 1999). The importance of caregiver coping styles is summarised well by Shah, Wadoo and Latoo:

> *'Caregivers need to have the opportunity to learn more effective ways of coping with stress. If they can learn new ways to cope, they can reduce their anxiety and reliance on treatment.'* (2010 p. 22).

Effective coping styles are of optimal desirability as they have the potential to negate the perceived strains of the caregiving role with minimal risk to the care giver or their relative (Savelkoul, Witte and Post, 2003).

6.8.1 Empathy for their Care Receiver

The caregivers made attempts to understand things from their relative's perspective. Such appreciation of their relative and their perspective allowed the caregivers to empathise and gain insight beyond their own perceptions. Greater understanding of what an ill relative is going through can facilitate the emergence of healthier adaptions to the caring role and improve health outcomes for both carer and relative (Brent et al. 2011). The empathy expressed by the caregivers to appreciate the vantage of their relatives facilitated the understanding and attribution of their behaviours.

The ability to attribute behaviours as symptomatic rather than as a result of personal intent is associated with coping styles that are less manipulative in dealing with their relative (Chakrabarti and Gill 2002), which indicates a change in behaviour through understanding the intentionality of symptomatic and challenging behaviours. Akin to the effects of learning about their relative's condition (Barrowclough and Tarrier 1992; Gerdener, Buckwalter and Reed 2002), empathy too appears to facilitate a clearer and more positive perception of their care receiver which can cultivate beneficial health outcomes for both carer and relative.

Research has shown that the capacity to learn more about a relative's condition is not dependant on emotional state (Braithwaite and McGowan 1993). The lack of difference in information uptake between caregivers regarded as experiencing emotional stress and those not, indicated that this ability to learn more about a condition is not limited to caregivers who are well or already adapted to the role.

Such a capacity for empathy has clear benefits but the nature of empathy itself can be tiring and it has been found that those providing professional health care can experience a sense of 'compassion fatigue' (Weiss 2004) which is exacerbated by care recipients who are stressed or distressed (Shapiro, Brown and Biegel 2007). Such burnout can be detrimental to a caregiver and can lead to increased levels of anxiety and depression (Radeke and Mahoney 2000) and decreased self-esteem (Butler and Constantine 2005).

Lack of illness awareness can exacerbate negative consequences of the role through misunderstandings, conflict and interpersonal social dysfunction (Berk et al*.* 2013). It is therefore important to ensure that such empathic attempts are controlled and presented with opportunity of self-fulfilment too.

6.8.2 Self Awareness

The capacity to reflect on ourselves, who we are and why we do what we do is termed self-awareness (Shapiro, Brown and Biegel 2007). The process of self-awareness allowed the participants in this study to understand better their own motives and intentions in the caring role. Introspection can facilitate personal change for the better through recognising the emotions associated with how and why we act the way we do (Richards, Campenni and Muse-Burke 2010). Increasing the capacity for self-awareness in caregivers has the potential to facilitate self-care through introspection and self-actualisation (Mearns and Thorne 2007). Enabling caregivers to monitor their own emotional and behavioural reactions to challenging aspects of the caring role could reduce negative health outcomes, by having the caregivers themselves replace ineffective or harmful methods with beneficial ones.

6.8.3 Communication

Communication was reported by the participants as a social and interpersonal adjustment recognised to have cultivated from trial and error. Aspects such as learning to avoid bandaging statements and engaging in true and open dialogue were reported to be very beneficial, and arose through the cumulative appreciation for these abilities over time. The caregivers recognised that this was not always easy as communication with their relative, especially when in enhanced mood states, took patience and self-control. Savundranayagam, Hummert and Montgomery (2005) reported the importance of communication between caregivers and care recipients following 89 caregivers for persons with dementia self-reporting on various measures related to communication and the caring role. The authors suggested that poor communication was related to problem behaviours in the care recipient.

Such an investigation has not yet occurred for those caring for persons with BD but the participants interviewed in this study appeared to rely upon communication to facilitate the sociodynamic intercourse between themselves and their relatives. If communication leads to decreased challenging behaviours as claimed by Savundranayagam et al., then the benefits for caregivers of persons with BD could benefit from such changes to rebuff the challenges of dealing with such behaviours which impact so heavily upon them. Other factors associated with less frequent positive communication include lack of awareness regarding care receiver illness, social withdrawal and talking less with friends (van der Voort, Goossens and Bijl 2007) which reflect the multifaceted benefits of communication and the overarching benefits it can produce.

6.8.4 Acceptance

Acceptance for the caregivers appeared to be acknowledging that things have changed and are unlikely to be the same way again. The previously mentioned work by Rose, Mallinson and Walton-Moss (2002) in the Section 6.7.2 in this Chapter relates to this mind set, in that a certain extent of experience and recognition must occur to facilitate acceptance of the situation. Such acceptance focused on the change from being a relative to being a carer and the relationship dynamics, responsibility modifications, and re-planning of the future. Acceptance following the potential shock and grief associated with a relative becoming ill appears to be yet another process dependent upon experience as a caregiver (Champlin 2009).

Caregivers who are less controlling over what they believe their care recipient should be doing were found to display higher levels of acceptance of the caregiving role (Hooley 2004). Such attempted regulation of care receiver behaviour is indicative of low awareness of illness behaviour (Kuipers 2006) and could, therefore, potentially be remedied by understanding more about the behaviours and symptoms of BD. Facilitating acceptance with caregivers is an important aspect of further adaption to the role once the caregiver is in a place where they can come to terms with their situation and being able to make changes for the better (Rose, Mallinson and Walton-Moss 2002). However, acceptance does not refer to a *laisez-faire* attitude of apathy and resignation and is summarised well by Dorian *et al.*: *'Acceptance involves a lower need for overt change through awareness and understanding which may in turn* *lead to solutions to problems, rather than becoming emotionally withdrawn or overinvolved.'* (2008, pp. 224).

6.8.5 Avoidance

Avoidance can be understood as 'escape behaviour' or 'wishful thinking' and use of such coping strategy has been reported as high as 82% by caregivers of a person with BD (Nehra et al. 2005). Unlike the previously reported coping styles reported by the caregivers, avoidance comes with negative associations rather than positive. The use of such passive and cognitive avoidant strategies are related to higher rates of depression, decreased care giver/receiver relationship cohesion and diminished social outcomes (Chakrabarti and Gill 2002; Shah, Wadoo and Latoo 2010). The use of avoidance arose when the caregivers felt they had neither the resources nor the ability to deal with a presented problem or challenge. Recognising the use of avoidance also led the caregivers to feel frustrated with themselves for retrospectively deeming their efforts as inadequate. Therefore, providing caregivers with the opportunity to learn different ways of coping may reduce the reliance upon avoidance as a last resort when no other options seem viable. Replacing avoidance with a more beneficial coping style would improve the health and wellbeing of the caregivers.

6.8.6 Enjoyable Activity

Taking time and energy for one's own needs relates to the self-fulfilment/effacement dilemma discussed previously. The caregivers reported that self-fulfilment could be attained through taking time out and doing something for themselves. Such efforts may defend against the aforementioned loss of identity through maintaining a component of attending to the self. Engaging in personal pursuits, can aide against the loss of self that accompanies the adoption of the caring role (Grant and Davis 1997). When Lam *et al.* (2005) interviewed people who had previously been caregivers for persons with BD but had not remained in the role and divorced their spouse, they reported that the thing they most identified retrospectively that should have happened differently is taking more time out for themselves and fulfilling their own needs. Caregivers who actively seek out time to spend on personal activities they enjoy have reported an emotional cathartic experience from doing so (Chambers, Ryan and Connor 2001).

Taking the time to engage in an enjoyable activity clearly benefits the caregiver through the process of self-fulfilment and maintains aspects of self-identity. Consideration should, however, be paid to the conflicting influences of ‘Bound to the Care Receiver’, whereby the caregivers experienced increased anxiety, worry and guilt when separated from those they cared for. Those caring for a relative with BD are more likely to have to sacrifice leisure time than caregivers of persons with other mental health conditions (Rusner, Brunt and Nystrom 2008). To mediate this, efforts should be made to elicit the benefits of engaging in self-fulfilling activities and having one’s own space without requiring too much dissociation from the caregiver’s relatives, to strike a balance of the two facets of the role, and to enjoy personal time and space whilst not inducing negative emotions of detachment.

6.8.7 Peer Support

Peer support refers to the experiences that the caregivers had when talking to others in the same situation as themselves: caring for a relative with a mental health condition. Such peers were found in friends and acquaintances who were also caregivers or through organised peer support groups. The coping mechanism of peer support differs from the others elucidated from the caregivers’ experiences in that the process involved others out with the caring relationship. Low satisfaction with perceived social support is predictive of self-reported burden (Creasey et al*.* 1990; Li et al. 1997) so is evidently an important aspect of solace for those providing care.

What places *Peer Support* in the theme coping style rather than in *Support Received* is the means by which the caregivers utilise peer support. The utility of peer support was to share experiences, validate methods and feel a sense of kinship through commonality. This contrasts from engaging in support from friends, family and professional healthcare workers as the key difference here is ‘peer’ support through which the caregivers perceive help or assistance from those in similar situations whereby advice or support is seen as mutual rather than empathic, as understanding in peer populations is innate and lived rather than learned (Charlesworth *et al.* 2011).

Pillemer and Suitor (2002) investigated the isolated effects of peer support from social support interventions as they hypothesised that other confounding influences such as education, counselling and direct service availability could create a false positive in the perceived benefits of peer support. The authors found no main effect of peer support in isolation of other aspects of social support which questions the sole beneficence of peer support for caregivers. Despite a lack of main effect of peer support, over 95% of participants reported the peer support sessions to be useful and positive.

A possible suggestion for reported beneficence in the absence of statistical significance was offered by Heller et al. (1991) who suggested that there may be short lived benefits to peer support from subtle mood changes. These effects were thought to dissipate over time and exist as a temporary increase in satisfaction through experiencing a sense of experiential similarity (Pillemer and Suitor 2000). Such dissipation would suggest that peer support itself is not responsible for the longer term benefits of social support reported. From the participants in this study, of those who spoke strongly for peer support talked about their experiences in the present tense indicating that they still engaged in social support so if the benefits of such a coping style dissipate over time, such time had not passed for these caregivers.

6.8.8 Problem Solving

The coping style of problem solving may at face value appear to be the experience of all coping styles that have arisen through experiential adaption but the theme of problem solving reflects a dynamic and continuing strategy implemented by the caregivers to manage situations through active situation assessment. The major component of such behaviour was an understanding of their care receiver and triggers of mood states. The caregivers had learned through experience what environmental, interpersonal and emotional influences impacted upon their relatives and sought ways to predict and avoid these. These constructive efforts allowed the modification of situations and were pre-empted by the caregivers showing a great deal of forethought, insight and planning on their behalves.

Higher levels of adaptive behaviours as such are associated with more efficient social discourse in the caring relationship and lower levels of perceived distress (Chakrabarti and Gill 2002). Problem-focused styles of coping are more successful for caregivers than emotion-based or psychologically focused coping styles (Shah, Wadoo and Latoo 2010), suggesting that this ability to assess situations through a greater level of interpersonal caregiver knowledge is of optimal benefit. Such knowledge required to provide high quality problem solving abilities based on interpersonal traits and characteristics of their relative is thought to develop through a strong emotional bond created by the caregiving experience (Chamber, Ryan and Connor 2001; Miklowitz and Scott 2009). It may be this inherent adaption of problem solving and understanding that arises from the informal caregiving relationship that differs from a professional or clinical caregiving relationship and provides the reported advantage found when relatives care for their own (Lincoln 2000; Deekan et al. 2003; Rusner et al. 2012).

6.9 Support Received

Support was reported to have been received from friends, family and professional healthcare workers. All three avenues of support received both positive and negative evaluation by the caregivers and this perspective appeared stringent upon the perceived intent of this assistance rather than the quantity provided. A lack of such social support is thought to be an underlying contributor to negative outcomes of the caregiving role such as burden, isolation and loneliness (Chambers, Ryan and Connor 2001; Demirtepe-Saygılı and Bozo 2011). Social support is defined as *'the perception or experience that one is loved and cared for by* *others, esteemed and valued…'* (Taylor 2011 p.189). However in regards to informal caregivers, this concept appears to determine not only upon perceptions of support for the self but also for their care receiver and the support they receive.

6.9.1 Family and Friends

When the caregivers reported support from family members and friends they discussed being helped personally and indirectly through relief from routine support provision. Having someone to talk to honestly and openly was of paramount importance and required a perceived trust of the person being spoken to. Assistance with routine care tasks allowed the caregivers the time and capacity to focus on other essential aspects of their lives such as work and family. These forms of assistance were seen as positive and were appreciated by the caregivers. Such support is reported to satisfy attachment needs, improve self-worth and relieve stress (Klienke 1991). The benefits from friends and family can, therefore, improve the caregiving experience, and work should be undertaken to try to enhance the psychosocial capabilities of caregivers to actively seek such support to ensure these needs are met (Cooke et al. 2001).

However, support could also be seen to be negative and even detrimental to the care of their relative. Such ill regarded assistance concerned a lack of understanding or appreciation of mental health and the challenges the caregivers and their relative faced. Relating to *Quality Care for the Care Receiver*, if external assistance compromised or was not congruent with the standard of care that the caregivers felt they provided, it was deemed as unhelpful. Such information is beneficial in understanding how to initiate the provision of assistance for caregivers as attempting to deliver an unjustified or contrasting approach to care provision may be treated the same way.

6.9.2 Healthcare Professionals

A degree of experience was presumed by the caregivers in relation to those whose occupations ARE involved in mental health care and the care of their relative. Akin to support from friends and family, support from healthcare professionals also received positive and negative reports. Support was deemed positive when the caregivers felt that their relative was being treated in regards to being an individual, and when professionals treated both themselves and their relative with respect. The caregivers felt that they had a plethora of experience from which individualised care for their relative could be extracted and utilised. In this regard, the feeling of being listened to was important. In relation to person-centred care, the ability to develop such care could greatly be benefited through greater utility of the personal information possessed by the caregivers.

Exploring the experiences of caregivers for a person with BD, Maskill et al. (2010) found an overall negative experience of mental health services as they were not providing the support that the caregivers expected. This is also seen in this study whereby the negative experiences of mental health care professionals are related to difference of opinion regarding care between professionals and the caregiver. Kaas, Lee and Pietzman (2003) identified those healthcare workers' opinions regarding family and the care they provide can be disapproving and therefore unhelpful. Efforts could be made by those working with patients and families to explain care plans to caregivers in order to aid the understanding and rationale of actions taken regarding the care of their relatives. However, potential confidentiality issues could arise in relation to the care receiver's rights.

Maskill et al. (2010) did report isolated positive encounters with *certain* staff members who had treated them well which indicated the capacity for congruence of expected care by the caregivers and care provision by professionals. This is also seen in the study through caregivers feeling attended to and listened to by particular members of mental health care teams. The difficulties of health professionals in providing information to family members in relation to time and confidentiality have been recognised (Wilkinson and McAndrew 2008; Berk et al. 2013) but a deficit of this care provision has obvious detriment to the perceived care of the care receiver and their family. Some evidence even exists to show that a caregiver who feels uninformed may discourage against advised treatments and negatively affect medication adherence (Sajatovic et al. 2009) showing that caregivers have the capacity to be detrimental to care receivers' health when uninformed.

6.10 What's Wanted

Two desires were prominent from the caregivers, to receive carer-centric support and to have healthcare professionals pay credence to their opinions of care for their relative. There was an expressed need for support for caregivers, from a dedicated source of emotional support, guidance to provide a reliable foundation for caregivers to understand the potential life changes the caregiving role creates. Whilst healthcare professionals have the capacity to decrease levels of burden in caregiving populations, there are further emotional needs and support that cannot be met through these means (Rose 1997). Considering the consequences and implications of caring for a mentally unwell relative, the caregivers face a plethora of psychosocial strains (Steele, Maruyama and Glaynker 2010), it is therefore unsurprising that caregivers desire the support that is carer-centred.

Regarding collaboration with healthcare professionals, the participants acknowledged their own experience and expertise of the care and mental health of their relative and felt underutilised when care plans were created. The creation of variance in care provision without the caregiver understanding why, can increase strain and reduce locus of control (Rusner et al. 2012). Such negative effects can be avoided with explanation of the care plan to caregivers so that the support they provide for their relative can be congruent and informed (Rowe 2011). These effects should be considered regarding the inclusion of caregivers in the care for their relatives despite the challenges of confidentiality, as feeling excluded or ignored by healthcare workers can lead caregivers to feel isolated, powerless and frustrated (Magliano et al 2004; Wilkinson and McAndrew 2008).

The insights that caregivers have, not just in regards to their own experiences, but to the care and wellbeing of their relative should be considered with higher regard by healthcare professionals. As described and discussed in the previous themes, the caregivers constantly experience BD alongside their relatives and have adapted to the caring role to best provide a high standard of personalised care for their relative that may not be achievable by a professional caregiver.

The qualitative results show eight major themes that express the lived experiences of those caring for a relative with BD. This is the first study to use Gadamerian hermeneutics to draw out such information from this population and shows a depth and uniqueness of experiences. It is from this rich data that the quantitative results could be produced through the intervention and assessment. These results are discussed as feasibility, acceptability, meaningfulness and effectiveness.

6.11 Feasibility

In regards to recruitment for the study, it should be noted that carer centre response rate was over a third. The reasons for lower response rates may be attributable to variance in carer centre organisation, and resources to reply to such requests or that those who attended the centres were caregivers of persons with other forms of ill health. The majority of participants were recruited through this means, but almost a third were still recruited through dissemination of the study recruitment information. Those caring for relatives with BD are a subset of caregivers that are difficult to reach directly.

Those of whom that have interacted with services such as carer centres are more easily reached, and may be more likely to take part in such studies like the one reported in this thesis (Berk 2013). Carer centres should be considered as a primary source of recruitment but perhaps recruitment could be enhanced by those involved in the study presenting the information and opportunity in person rather than through a mediator. This would allow for direct contact to provide any further information and better explain the necessity for such studies. It would also reduce the reliance upon third parties acting as a gatekeeper, the influences of which may limit which persons have access to the information.

Other means of recruitment are also important as those who have not made contact with carer services may differ in their caregiver needs and perceptions of their experiences. Dissemination of the study should be as wide as possible to reach as representative and numerous samples as possible. Regarding participant retention, the current intervention was both complex and longitudinal; a factor that has been shown to reduce participation rates, but experience only a 35% drop out. This level is comparatively positive compared to other intervention studies, even those that utilised less complex interventions (Bernhard et al. 2006; Jonsson et al. 2011; Madigan et al. 2012). This may be attributable to the intervention having been developed based on lived experience, a factor that has been recommended in caregiver intervention studies (Ogilvie, Morant and Goodwin 2005). The initial dropout of 13% reflects those who perceived participation to be too demanding and may be due to increased caregiver demands or perhaps reasons ascertaining to individual differences. As participants who dropped out prior to baseline collection did not return any information, no sociodemographic information could be attained by this group.

Those who remained in the study may have done so as enthusiastic or interested participants which would affect their outcomes of such an intervention positively (Jamison 2000). Committed individuals would not be representative of the caregiving population as a whole and were this case; the outcomes would be biased towards effectiveness. Conversely, the caregivers who remained in the study may have done so as they were requiring assistance, and want their experiences heard. The outcomes of any intervention must consider dropouts to have a potential bias as circumstantial barriers to committing are representative of the population as a whole whereby not everyone would desire, commit or take interest in interventive assistance (Thebane et al. 2010).

Future studies should consider further exploration of those who drop out, possibly by contact, asking for their participation in the provision of just these limited sociodemographic information, to help ascertain if a subset of caregivers are less likely to engage in interventions at all. Should such a subset exist, it would be beneficial to understand the factors around this, not just to highlight potential confounding factors in recruitment, but to allow extra attention to be targeted where it is needed, to ensure equal opportunity amongst the caregivers to engage in intervention assistance.

6.12 Acceptability and Meaningfulness

The participant ratings of the four components, provided component consistent scores, in that the four components scored equivocally in all four aspects. The psychoeducational component was scored the highest and bodes well for the prominence of psychoeducational approaches to caregiver interventions. The cognitive behavioural and social skills components were rated similarly below that of psychoeducation and scored close to the mean score for all four components, as displayed in Table 1. The mindfulness component scored lower than the other three components in all reported aspects of acceptability and meaningfulness. These results show that there exists scope in which to modify the lower three scoring components in order to increase their acceptability and meaningfulness to the level of a psychoeducational component. Also, the scoring patterns indicate that the four aspects measured: usefulness, ease of understanding, interesting and facilitated change, are equally understood across each component.

When the mean scores for each feasibility measurement are considered we can see that the participants thought the psychoeducational component was the easiest to understand, most useful, most interesting and most facilitating of change. This strongly supports the inclusion of such a psychoeducational component as part of a complex intervention for those caring for relatives with BD. The cognitive behavioural and social skills components scored close to the average of the intervention as a whole. The scores for these components show that they were well accepted and perceived to be meaningful, but could possibly benefit from slight revision by comparison to the psychoeducational component. However, as no study to date has compared these participant reported measures for these particular intervention components in caregivers, it may be that each component reaches a ceiling effect at different ranges based on the very nature of the component itself.

A lower score was received for the mindfulness intervention which reflects a lower perceived acceptability and meaningfulness of this component by participants. As the benefits of mindfulness have been shown for caregivers, it would be reasonable to include a mindfulness component in future interventions for this population but pay higher regard to boosting these aspects. This may be achieved through further explanation of the purpose of the component and its intentions. As the mindfulness component required participants to practice several exercises, the nature of self-care limits the ability to monitor and encourage these activities.

Glük and Maercker (2011) made use of multimedia such as animated exercises and interactive tasks but failed to produce any change in mindfulness, reflecting that interactivity alone may not be the key enhancing caregiver involvement. Perhaps content could be recorded to guide these mindfulness exercises to facilitate the correct procedures and durations of the exercises, whilst allowing proficiency to coalesce with a lesser reliance upon self-organisation to practice. The lower completion rates, especially of the mindfulness component, indicate lower levels of interaction. Self-care interventions are privy to the effects of individual inspiration and commitment, nonetheless, objective results regarding interaction with components equally reflects positive engagement with the intervention components.

6.13 Effectiveness: Component Interaction/ Assimilation

The four intervention components: psychoeducational, cognitive behavioural, social skills and mindfulness, were selected following the outcomes of Stage One and are justified in Stage Two, and piloted in Stage Three. Each component required individual assessment of the assimilation of content which would have led to changes perceived by their dedicated assessment tool. A significant change in the associated behaviour shows interaction with the intervention component as interaction led to behavioural and/or cognitive change.

6.13.1 Psychoeducational Component

Following the psychoeducational component of the intervention, participants showed a significant increase in their understanding of mood disorders and illness awareness compared to the control group. These results support the findings of other psychoeducational intervention studies with the same population (Bland and Harrison 2000; Madigan et al. 2012). Both the Facts and Symptoms subscales were significant showing that both understanding of the illness and recognition of illness behaviours had improved. Improvements in illness understanding have been shown to improve caregiver psychological health (Katz, Irish and Devins 2004; Visser-Meily et al. 2005; Hudson et al. 2012) and quality of life (Northouse et al. 2012).

Not only does caregiver health benefit from this increased understanding but it is reported to alter their caregiving approach whereby higher understanding of the illness leads to a higher awareness of illness related behaviours. This alteration of perception is evidenced in the increase in attributed symptoms reported by the caregivers. In disassociating symptoms with the care receiver and rather attributing them as illness related interpretation of caregiving situations result in lower psychosocial deficits (Miklowits and Hooley 1998; Goldstein, Miklowitz and Richards 2002; Fristad, Gavazzi and Mackinaw-Koons 2003; Eisner and Johnson 2008).

Not only did the psychoeducational component facilitate these changes in understanding and symptom attribution but it also provided caregivers with a reliable and understandable source of information. This is reflected in the high participant ratings for this component and can be evidenced from the optional additional feedback.

"I had previously not found a one/off, easily understood source of info. to which I could refer whenever I had a query."

"It has been great to have all the information I need in one place. Before it has been hard to know where to turn to and how to get info."

The restricted access caregivers have to information (Berk et al. 2013) evidences further the necessity for psychoeducational intervention as these caregiving benefits are far less attainable to those of whom have little or no access to information they feel they can trust. Understanding relatives' behaviours in the context of BD may present challenges not evident with other conditions, as the dynamism of mood states could prove confusing in illness comprehension by caregivers. Caregiver strains are evidenced during care receiver euthymic states which indicate misattribution of symptoms can increase the level of negative consequences through misinformed judgements. Further exploration of caregivers during this euthymic stage following psychoeducation could provide insights and greater understanding of the extent to which illness behaviour understanding alleviates this consequence.

In Stage One of the study, participants reported suicidal ideations and behaviours as the most incomprehensible and stress inducing. The psychoeducation component attended to this problem with a dedicated portion relating to suicide, suicidal thoughts and how to interact with someone expressing these. As this issue was highlighted as a high burdening aspect of the role, attendance to this may have contributed to the high participant perception scores. The inclusion of such content is recommended in future intervention development for caregivers of relatives with BD to ensure these recognised needs are met.

6.13.2 Cognitive Behavioural Component

In comparing the intervention and control groups, participants reported significantly fewer negative automatic thoughts but no such change was observed in positive automatic thoughts. The lessened quantity of negative automatic thoughts evidences that the attempts at cognitive restructuring were successful, however only to a point. The significant decrease in automatic thoughts is beneficial in displaying that cognitive behavioural interventions can increase the health of caregivers of relatives with BD using direct and validated assessment as opposed to studies that have claimed such an effect without valid evaluation.

Negative automatic thoughts in caregivers have been shown to decrease adaptive behaviours to the demands of the caregiving role (Chang 1999), therefore a reduction of these would indicate the propensity to adapt in healthier ways (Márquez-Gonzalez et al. 2007). Caregiver psychosocial health is greatly impacted by the means caregivers react to stressors (Herbert et al. 2003), so a reduction in negative thoughts that facilitates adaptive behaviours would also lead to improved psychosocial functioning. Several caregiver cognitive behavioural intervention studies reported limited or lack of, effectiveness of this means of intervention (Gendron et al. 1996; Chang 1999; Wilkins et al. 1999; Herbert et al. 2003) and the results of this pilot study challenges this assumption. The positive effect found in regards to cognitive behavioural change enforce the need for direct measurement and also reflect that a propensity for carer-centric cognitive changes may not be the most accurate way to approach intervention with caregivers as automatic thoughts unrelated to caregiving but focused on the self could also greatly impact their responses to the demands of the role.

If the study had focused purely on health and not included wellbeing, it would have been concluded that the cognitive behavioural component was entirely successful. Nonetheless, without an increase in positive automatic thoughts, the attempts at cognitive restructuring managed to reduce the processes that lead to harmful ways of thinking but did not manage to restructure the enhanced formation of healthier enforcing thoughts. The need to regard positive aspects in the caregiving role is evident (Hunt 2003; Koerner, Kenyon and Shirai 2009) and these protective factors have the potential to provide great benefit to both caregiver and care receiver. Further work should continue to explore how to instil positive thoughts in caregivers as these have been identified as generators of change that facilitate flourishing (Fitzpatrick and Stalikas 2008).

The resultant change in automatic thoughts following the intervention display a strong support for the use of cognitive behavioural intervention for those caring for a relative with BD, but indicate the need for further research in to instilling positive thoughts. From participant feedback, the efforts to instil these automatic thoughts were received well despite the overall lack of change in these:

> "Did all the exercises. Some of automatic thoughts made me think what was and wasn't important to get 'her up about' i.e. 'Standing Back and view the situation'. Made me realise what qualities I had. Improved my self-esteem. Shall do more 'Automatic Thought' exercises when feeling low."

6.13.3 Social Skills Component

With the social skills measurement, neither subjective nor objective measures of social support changed for the intervention group when compared to the control group. The social skills component was the only component of the four piloted within the intervention that was evaluated to show no significant increase in outcomes reflecting interaction with the component. Referring to the reported acceptability and meaningfulness scores from participants, the social skills component scored very closely with the cognitive behavioural component which did produce a significant effect. The social skills component was selected to increase the social abilities and understandings of the caregivers so that they could seek out and maintain healthy supportive relationships (Robinson 1988; Hansell et al. 1998).

The results from the SSQ-6 did not reflect a change in this, evidencing insignificant improvement in neither the quantity nor the perceived quality of support received. Social support for caregivers has been shown to mitigate the effects of challenging behaviours both objectively and subjectively (Pistrang and Barker 1998; Chakrabarti and Gill 2002; Pakenham et al 2007), improve wellbeing (Lincoln 2000) and improve perceived situational control (Atienza, Collins and King 2001). However, these outcomes may also be influenced by the other three components in the intervention and could not be used to evaluate interaction with the social skills component. From participants' feedback (See Appendix Twelve for full list), a potential display of information assimilation was noted:

> "This is the section that has most helped me to improve communication with my son. He is "male" + quiet, I am "female" + very talkative generally!"
>
> "Really made me realise how to talk and how to listen. I was not sure about this to start with as I thought how easy and simple this would be but the way it is explained is not like being talked down do and is clear and useful. Helps when speaking to my husband so I am listening more."

It would appear possible that caregivers did interact with the social support component to a greater degree than was reflected in the evaluation. Measuring social support rather than social skills was justified through the relationship these factors shared, and that increased social support was originally the main ethos for this particular component. However, from participant feedback, we gain an indication that the social skills learned from the intervention may have been put to use to enhance communication with their care receiver, perhaps seen as a more critical factor by caregivers than seeking external support. In regards to professional caregivers, a relationship between caregiver and patient that is mutual whereby power is shared is related to improved control of chronic illness (Martin, Haskard-Zolnierek and Dimatteo 2010).

Potentially, increased communication skills gained from the component could lead to the fostering of these types of relationships where both the caregivers and receivers feel they are understood by the other. Such social dynamics would improve the health outcomes of the care receiver through this change in communication which would also reduce aspects of caregiver burden related to difficulties with interpersonal dynamics.

Future interventions with caregivers of a relative with BD should focus upon the relationship between caregiver and care receiver in relation to communication and social discourse to further investigate this potential benefit of social skills intervention. The results obtained in this pilot study therefore do not indicate a lack of usefulness of social skills intervention but do provide evidence to suggest that the ambitions of enhancing social support through self-care intervention cannot be achieved by social skills training.

6.13.4 Mindfulness Component

Overall, the mindfulness component was not significantly different between the intervention and control groups at follow up but analysis of the individual facets of mindfulness revealed a significant increase in the observe and awareness subscales, and results approaching significance for non-reactivity. The facets of describe and non-judgement were non-significant reflecting a lack of change in participants' ability to describe feelings and accept them without judgment. The mindfulness component was therefore unable to prompt participants to explore feelings intently enough to be able to articulate and understand them without verdict. The exercises in the mindfulness component did not actively encourage participants to describe thoughts and feelings, rather than recognising them which may account for this outcome. Non-judgement on the other hand, was encouraged but caregivers may be at greater liability of judging actions and being self-critical than non-caregivers, thus requiring greater efforts in training this facet of mindfulness (Skovdahl, Kihlgren and Kihlgren 2004).

The score for the awareness and observe facets significantly increased following the intervention showing that the component was successful in instigating the ability to monitor feelings and also to maintain focus upon them. The exercises such as the body scan placed an emphasis on observing the feelings, thoughts and moods of the present moment, and trained participants to maintain focus of their attention. The ability to recognise and monitor inner experiences with awareness would allow the caregivers to keep track of their thoughts, moods and feelings and be able to maintain concentration to the present moment. Ruminating over past events or concerning future potential outcomes, can lead to psychological deficits such as depression and anxiety which can be addressed with mindfulness practice (Grossman et al. 2010; Deckersbach et al. 2011; Robin et al. 2012).

The observational and awareness skills, coupled with a positive trend in non-reactivity, may well contribute to a reduction in such outcomes. Restrictions of this benefit may arise due to the limit of the facets of mindfulness that were significantly enhanced, as such effects have been reported for mindfulness when evaluated as a single outcome.

Future mindfulness components should more actively encourage the descriptions of inner experience and address the self-critical nature prominent in caregivers. If such efforts were undertaken, the full five facets of mindfulness could be induced through self-care intervention and provide the associated benefits of increased mindfulness. As discussed earlier in this chapter, the acceptability and meaningfulness reported by the caregivers was lowest in all aspects for mindfulness and participant feedback reflects the difficulties some faced:

“I have a “butterfly” brain so the exercises were difficult! I did, however, benefit from realising that I must at times make my own well-being a priority in order to benefit the longer term situation with my son.”

“Taking time out to do this was a big help. The exercises started to get easier and I will definitely keep this up. Really liked it even though it was difficult to start with.”

The mindfulness component was also the least completed according to self-reported percentage of engagement. Further delineation of mindfulness and a method akin to providing audio instructions for mindfulness practice may increase the engagement with such a component and possibly lead to a greater increase in the facets of mindfulness than found in this study. The mindfulness component was originally considered to provide caregivers with a sense of their own space and this was also reflected in feedback:

“It encouraged me to “actively” take time off, just concentrating on something nice (and for myself) for a little time. It’s relaxing and gives you new strength.”

“Improved quality of life.”

The very act of taking time to practice mindfulness may have contributed to beneficial changes such as increased self-esteem, self-effacement and acceptance that have shown relationships with actively engaging in personal activities not related to caregiving (Martire 2005; Ross 2008). Glük and Maercker (2011) have recommended the comparison between mindfulness and standard relaxation interventions to examine the potential influences of scheduled relaxing against the claimed influences of mindfulness itself. Future interventions should consider the measurement of such outcomes to identify if the act of engaging in mindfulness practice can provide benefits to health and wellbeing in addition to the benefits of increased mindfulness alone.

6.14 Effectiveness: Health and Wellbeing Outcomes

The health and wellbeing outcomes measured wellbeing, coping styles and resilience. Positive changes in these reflect benefit from engaging in the piloted intervention. However, it should be noted that with several components, these effects cannot be directly attributed to one particular intervention component but rather the complex intervention as a whole.

6.14.1 Wellbeing

Wellbeing was found to be significantly increased following intervention. In the caregiving population, wellbeing correlates highly with psychological outcomes such as depression and anxiety (Orgeta, Sterzo and Orrell 2013) indicating that as wellbeing improved through participating in the intervention, that these health outcomes also improved. Wellbeing refers to more than just health however, as it includes positive mental health

(Langeland et al. 2007; Tennant et al. 2007). The ATQ-P failed to report any significant increase in positive automatic thoughts in the caregivers who participated in the intervention but a significant increase in wellbeing shows that positive effects were instilled. Wellbeing measures beyond automatic thoughts, which may be limited by caregivers recognition or reluctance to report positive aspects of the role (Wennerberg, Lundgren and Danielson 2012), and encompasses life satisfaction and psychological functioning.

These results demonstrate that the piloted complex intervention has the potential to enhance both health and wellbeing in caregivers of relatives with BD. The lack of positive automatic thoughts reported should be noted and considered when measuring positive effect rather than the assimilation and interaction of a cognitive behavioural component, as there is a potential for caregivers to underestimate positive change in regards to automatic thoughts alone. The proposed converse relationship between burden and wellbeing (Stull, Kosloski and Kercher 1994) provides the insight for potential reduction in burden. Although this study did not use burden measures as they lack operational definition, the relationship the concept shares with wellbeing reflects that burden was also decreased following engagement with the intervention.

6.14.2 Coping Styles

The overall coping score did not change significantly between groups over the four month test period. However, the JCS overall score measures coping styles regarding as both healthy and unhealthy and no significant changes in ways of coping cannot be interpreted in this context. When the intervention group was compared to the control group at follow up, the use of confrontive and self-reliant coping styles significantly increased and those of fatalistic and palliative methods significantly decreased in use. As for the perceived effectiveness of each coping style, the optimistic and self-reliant coping styles increased and those of emotive coping styles decreased.

An increase in the use of confrontive and self-reliant coping styles would result in more constructive, problem-solving behaviours and depending upon themselves respectively. This change in behaviours would result in healthier and adaptive responses to challenges and increased self-reliance is indicative of a self-care approach. The decrease in use of fatalistic and palliative methods of coping would result in fewer behaviours that aimed to placate stress, such as eating, drinking or taking medications and being less likely to have hopeless and pessimistic attitudes in dealing with challenges. The intervention facilitated an increase in healthy adaptive ways of coping and reduced the reliance upon less constructive, less healthy means. The adoption of healthier coping styles in caregivers has been found to be producible through awareness of care recipient illness and reduced burden (Chakrabarti and Gill 2002). The adoption of problem solving methods of coping over emotive means i.e. releasing emotions to reduce stress represent perceiving challenges as in one's own control (Östman and Hansson 2001).

Caregivers of relatives with BD have previously been administered the shortened version of the JCS following psychological intervention (Jonsson et al. 2011). The study also found a reduction in palliative and emotion-based coping styles but reported a significant decrease in confrontive coping styles also. The current study showed a more expected decrease in unhealthy coping only and improvement in adaptive coping following intervention compared to that of Jonsson et al. but this may be due to the multi-component aspect of the intervention. As self-reliant coping is not in the restricted JCS, the current study emphasises the capacity to fully explore the effects of interventions in areas where limited knowledge is possessed. Had the current pilot study also used the shortened version of the JCS, the improvements in self-reliant coping styles would have gone unnoticed.

The lack of change in optimistic and supportant styles of coping are consistent with the lack of change in positive automatic thoughts and perceived social support respectively. The congruence with these measures further enforces the results of the pilot study in regards to the benefits of health and wellbeing following the developed intervention. Changes in coping styles are clear indicators of behavioural change and the changes in both healthy and unhealthy coping styles are positive indicators that complex interventions have the potential to instigate significant positive behavioural change that results in enhanced health and wellbeing.

6.14.3 Resilience

Overall, resilience did not significantly increase following intervention but two of the three subscales: commitment and control, when analysed individually, did show significant improvement in score. Commitment refers to feeling deeply involved in the activities of life, and control refers to the inclination to influence outcomes personally (Kobasa 1979; Maddi 2006). Factors thought to mediate resilience in caregivers include taking time for oneself, self-efficacy and perceived support (Ross 2008). With the absence of change in the latter of these factors, taking time out for personal use may have been provided by the mindfulness component, as discussed providing a set personal activity, and self-efficacy from the psychoeducational and cognitive behavioural components whereby the caregiving role was made clearer in relation to BD, and caregivers were encouraged to challenge self-denying thoughts.

The stabilisation of caregiver outcomes such as strain and burden have been attributed to resilience and the development thereof across time (Gaugler, Kane and Newcomer 2007). Engagement with the intervention developed in this study instigated an increase in resilience in a relatively short space of time, increasing protective factors against the challenges and demands of the role. The subscale of challenge was not found to have significantly increased, however, referring to the belief that unpredictability and change lead to personal growth. It is possible that the caregivers are less inclined to respond to challenge items as routine, and reliability of care provision represent a consistent approach to the caregiving role, and disruption or change can lead to impaired care for their relative. Exploration of caregiver relationships with resilience, in particular the challenge component, could further the understanding of how caregivers develop resilience over time and how to fully instil this protective factor.

Resilience for the caregivers represents the protective factors of psychological traits and use of resources, and relating not just to coping in the caregiving role, but thriving. A whole state approach to understanding caregivers and the consequences of providing that care as positive aspects have been documented and provide positive consequences. The increase in both control and commitment represent a positive change in attitude and behaviours of the caregivers reflecting the meaning they derive from what they do and to what extent they are in control. These factors are related to self-esteem, self-efficacy and acceptance of the caregiving role which reduce negative reactions to stress and promote healthy ways of dealing with challenges. Despite the lack of change in the challenge subscale, the pilot of the intervention shows potential benefits with reference to resilience. Similarly, from the results obtained from the quantitative components of the study the following conclusions were drawn:

6.15 Chapter Summary

The pilot data obtained reflects the difficulties of recruiting a hidden population such as those as informal caregivers, but demonstrates the benefits of the informed development of interventions through the comparatively low drop-out rate for a complex intervention. Participant feedback showed strongest affinity for the psychoeducational component and least affinity with the mindfulness component. Information needs may prevail so strongly in caregiving populations that a reliable source of information is viewed very positively. The mindfulness component may have scored lower due to the novelty of such an approach and requires further research.

The lack of interaction with the social skills component compared to the positive interactions reported for the other three components may be through inaccurate focus of change elicited. Feedback from participants suggests that communication between the participants and their relatives were improved by this, rather than improving levels of social support as originally hypothesised. The psychoeducational, cognitive behavioural and social skills components provided results to show that participants had interacted with them and assimilated the information therein.

Wellbeing and the commitment and control facts of resilience increased significantly as did positive coping styles, while negative coping styles were also reduced. These changes in behaviours, cognition and protective factors demonstrate the means by which the health and wellbeing of informal caregivers of relatives with BD can be effectively enhanced.

Chapter Seven: Conclusions and Implications

7.1 Introduction

This chapter presents a summary of the overall results of the pilot study reported in this thesis. It includes reflections on the study, design of the study, appraisal of the strengths and limitations of the design and methods used original contribution to knowledge, limitations of the study, insights provided in Stage One and Stage Three of the study, the implications for practice, policy, future research considerations, and recommendations.

7.2 Reflections on the study

7.2.1 Overview of study

The aim of this pilot study has been achieved through the illustration of results and discussions provided within this thesis on the experience of informal caregivers providing care for a relative with BD, and the means to enhance their health and wellbeing. Stage One explored the lived experiences of this population of caregivers and provided findings to expand our previous limited knowledge and insights, in relation to both their experiences and consequences of their role. These findings have implications regarding future intervention development with this population.

Stage Two of the project involve intervention development and relied upon Stage One results and the recommendations of caregiver intervention research (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002; Ogilvie, Morant and Goodwin 2005; Reinares et al. 2006; Goossens et al. 2008; Thabane et al. 2010; Leon, Davis and Kraemer 2011) and the updated guidance of intervention development by the MRC (Craig et al. 2008). A robust and effective intervention requires that it is informed by the lived experiences of the intercept population, ensure sampling is not biased, control for confounding variables, include a control group for comparison to those undergoing the intervention, and be assessed using validated and direct assessment tools. This study serves as an example of robust and effective intervention design when adhering to these principles.

Stage Three provided original findings from the pilot of a unique multicomponent intervention. Feasibility data provides future large scale attempts, including a description of the intervention itself to allow for in-depth understanding and comparison with future work. Both the interaction with intervention components and health and wellbeing outcomes were documented and provide information pertinent to stakeholders with interest in intervention development, specifically for those caring for a relative with BD. Overall, the study has added to the growing voice of informal caregivers of relatives with BD by demonstrating effective and robust means of enhancing their health and wellbeing. Improvements in the welfare of caregivers benefits not only themselves but also those they care for (Lincoln 2000; Rowe 2011), and the healthcare services that are engaged with, when these caregivers succumb to the consequences in the provision of their high standard of care, as the 'hidden healthcare service' (Deekan et al*.* 2003).

7.2.2 Design of the Study

A sequential exploratory design was adopted, as mixed methods research can ensure a more in depth evaluation of intervention implementation by drawing upon the strengths of both qualitative and quantitative methods (Ivankova 2015). Gadamerian hermeneutic phenomenology was the philosophy used in Stage one, which places emphasis on deep understanding of lived experience (Binding 2008). This understanding is what is required in the initial qualitative stage of intervention development (Campbell et al. 2000; Craig et al. 2008) to ensure for effectiveness in both design and assessment. Such methodological and procedural rigour is recommended by previous intervention research to ensure the most effective development (Nolan, Grant and Ellis 1990; Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002).

The pilot of the intervention was operated to elicit the feasibility data of such an attempt (Arain, Campbell and Lancaster 2010), the effectiveness of each component within, and the positive potential changes in health and wellbeing outcomes. Such a design follows the MRC guidelines for intervention development and adheres to recommendations from intervention research (Craig et al. 2008).

7.3 Original Contribution to Knowledge

The significant original contribution to knowledge stems from, the use of hermeneutic phenomenology which enabled the illumination of new insights and depths of understanding of informal caregivers’ lived experiences in caring for relatives with BD, thereby adding new perspectives to this phenomena. This contribution to knowledge extends further the previous work of Rusner et al. (2012) who used descriptive phenomenology rather than the more robust hermeneutic process that seeks meaning through validation of the process (Annells 1996) and extends the methodologies of Bland and Harrison (2000) and Madigan et al. (2012) by providing a multicomponent intervention to increase understanding of different types of interventions rather than psychoeducation alone. The exploration of complex interventions had been suggested by previous research (Knight, Lutzky and Macofsky-Urban 1993; Sörensen, Pinquart and Duberstein 2002) and the updated MRC recommendations for intervention development (Craig et al. 2008).

Being Bound as found in the study, can be understood as the dilemma of requiring proximity to ensure care recipient safety versus taking one’s own space and suffering feelings of guilt and anxiety. This contradictory battle of self-fulfilment and self-effacement can be understood as a deeper understanding of a component of the broad theme ‘Struggling for Survival’ from the experiential study of Rusner et al. (2012). Being Bound has the potential to play a pivotal role in understanding how caregivers can make time for themselves, which will impact upon their identity, use of respite services and their own self-efficacy (Talley and Montgomery 2013).

The potential benefits of further understanding the Being Bound phenomena would facilitate future intervention assistance through encouraging caregivers to be able to take time to themselves, develop their identity and possibly engage more in beneficial resources.

The study as a whole provides an example of how to develop and pilot a robust multicomponent intervention for those caring for relatives diagnosed with BD. The health and wellbeing outcomes for those who took part in the intervention were improved compared to those who were not which demonstrates positive potential benefit. With inconsistent findings regarding the efficacy of interventions in previous research (Sörensen, Pinquart and Duberstein 2002), this study can help influence caregiver research towards effective outcomes in enhancing health and wellbeing.

The mixed methods nature of the study also produces novel contributions to knowledge through the lived experiences extracted from Stage One. Whilst finding new experiences of caregivers was not a direct aim of the project, the phenomenon of Being Bound was reported.

The pilot of the intervention provided insight in to the potential benefit of all four components within the intervention. Psychoeducation was scored highest with regards to acceptability and meaningfulness, and produced significant change in knowledge and understanding. The cognitive behavioural component reduced negative automatic thoughts but did not affect positive ones. This shows that such a component is useful in the alleviation of negative influences but would not benefit a whole state approach, and indicates little influence of this component to the observed change in wellbeing.

As the study was designed as a pilot, the results can be used for positive potential indications of larger scale attempts. The robust design of the study allows for a great deal of insights in to intervention assistance for those caring for a person diagnosed with BD and is further outlined in sections 7.5 and 7.6. in this chapter.

Previous caregiver research of those caring for someone with BD was limited to primarily psychoeducational studies that used therapist led interventions (Bland and Harrison 2000; Bernhard et al 2006; Madigan et al. 2012). This study developed a multicomponent intervention to show the benefits of four combined therapeutic approaches, and selected validated assessment tools to closely assess the degree of how well assimilated the information was of each one. The extent of changes in health and wellbeing following the intervention shows that complex interventions have the potential to create greater benefits to health and wellbeing.

The self-care aspect of the study emphasises both that caregiver’s possess the capacity to improve their own situation but also that this can be done through an affordable and standardised manner. Self-care interventions are accessible, affordable and could be less intrusive than therapist led interventions where participants have to travel, meet in groups and may be inclined towards socially expected responses for fear of being judged or stigmatised (Perlick et al. 2007).

7.4 Limitations of the Study

As with most pilot studies, the population used in Stage Three of the study is relatively small but sufficient for a feasibility trial. The findings of Stage three can therefore inform positive potential for the methods tested over statistical certainty. It should also be recognised that for caregivers to be currently providing informal care, the study’s method of sampling excluded those who were unable or unwilling to meet the demands of the role. Ex-caregivers could potentially possess different abilities, experiences and affinity for interventions than those who remain in the role. Understanding the experiences of those who were unable to become, or remain, informal caregivers may provide valuable information regarding the challenges of the role.

The weighted allocation to the intervention group at a 2:1 ratio to the control group was implemented to ensure sufficient data for the pilot study. Arguably, this process is not coherent with pure randomisation and may have attributed to selection bias; however, comparison between the two groups (intervention and control) showed only statistically significant difference in a single outcome: the perceived benefit of one particular coping method.

The longitudinal design of the pilot allowed the participants to engage with the intervention, as is seen in the results of Stage Three. However, due to the time constraints of this study, further follow up was not possible to observe if the effects of the intervention diminished or continued beyond for months post-intervention.

Mixed methodology can also be regarded as disadvantageous as sequential designs such as that performed in this thesis attempt to quantify rich qualitative data for the purposes of intervention development (Bazeley 2002) and can lose data in the process. Caution should always be used when attempting to use qualitative data as a means to an end and to ensure for legitimation of the process (Applebaum 2012).

7.5 Insights Provided by Stage One (Qualitative)

Stage One used Gadamer’s hermeneutic phenomenology to understand the lived experience of BD caregivers. Several previous efforts have been made using other variations of phenomenology to understand the lived experience of those caring for a relative with BD (Tranvåg and Kristofferson 2008; Rusner et al. 2012) and with general mental ill health (Chang and Horrocks 2006; Wilkinson and McAndrew 2008; Champlin 2009). The methods used by these studies did not fully utilise the phenomenological approach, evident in their restrictive or limited findings. This study proposes that the Gadamerian hermeneutic approach is best suited to understanding lived experiences when deriving them from transcripts of spoken interviews. The focus on language, tradition, ontological focus and the self-legitimising nature of the hermeneutic circle facilitates the extrapolation of rich and meaningful data that may otherwise be lost. This is evident in the range of data produced from the Stage One process, whereby a wider range of experiences were described compared to previous attempts with other methodological underpinnings.

The findings from Stage One compliment other caregiver intervention studies and provide direction for future research through the provision of a comprehensive display of the lived experiences of those caring for a relative with BD. The information need of this subset of caregivers was expressed in the same way as other caring populations (Rose 1999; Morris and Thomas 2002). The participants' scoring of the psychoeducational component of the piloted intervention strongly reflects this and iterates a need for a reliable and accurate source of information that caregivers have access to and can trust.

Positive aspects of the role were produced and are concurs with other studies focusing on caregiver experiences specifically related to the subset of BD (Maskill et al. 2010; Bauer 2012) whilst providing more comprehensive findings through the use of Gadamerian hermeneutics. Homage to positive aspects is not only critical in the holistic understanding of lived experience but to provide evidence of protective factors. Positive factors have the potential to benefit psychosocial outcomes (Hunt 2003; Stewart-Brown et al. 2011) and the participants in Stage One had developed and realised some of these, arguably to some extent, through their experiences. In order to instil these aspects that buffer the negative effects of the role, a further understanding of how caregivers thrive and remain well is required. This knowledge is reliant upon the understanding of these positive aspects of the role.

The findings regarding help from others can inform not just healthcare practitioners but also the lay public through the participants' perceptions of assistance from family and friends. External assistance was viewed as beneficial when it was perceived to be understanding of mental health and non-judgmental. By instilling this approach in the friends and families of those in an informal caregiver relationship, caregivers are more likely to make use of social support which has the potential to satisfy attachment needs, improve self-worth, lead to acceptance of the role and relieve stress (Klienke 1991; Cooke et al. 2001; Champlin 2009). Those working in the community have the opportunity to facilitate this approach in the potential social support relationships of caregivers to instigate the benefits of a healthy supportive relationship. Evidently, the lived experiences of those caring for a relative with BD have wide implications and not only serve to inform those working with said population but also to inform the development of robust and effective interventions.

7.6 Insights Provided by Stage Three (Quantitative)

The pilot intervention for this study consisted of four variations of self-care therapies: psychoeducation, cognitive-behavioural, social skills and mindfulness. Each component was assessed to determine interaction by using assessment tools that measured direct outcomes of these therapies. The importance of such scrutiny increases with the complexity of an intervention to ensure that components are not attributed as a false positive through the confounding benefit/detriment of a factor from other components. It was found that the psychoeducation component increased caregiver knowledge both in relation to BD itself and resulting symptoms. The cognitive behavioural component significantly reduced the presence of automatic negative thoughts showing potential benefit in cognitive restructuring. The mindfulness component produced an overall significant change but was limited in effect of the five facets that constitute mindfulness itself. The pilot study has shown that mindfulness has the potential to be beneficial in such an intervention but further investigation is still required to understand the relevant lay issues to be addressed.

The health and wellbeing outcomes for wellbeing and resilience were both effective, demonstrating that such a multicomponent self-care intervention does have the potential to enhance the health and wellbeing of informal caregivers of relatives with BD. Positive changes in coping styles was also observed with healthier methods of coping, such as self-reliant and confrontive, increased while detrimental methods of coping, such as palliative and fatalistic methods, decreased. The health and wellbeing of informal caregivers has been shown to be significantly less than non-caregivers (Maskill et al. 2010; Shah, Wadoo and Latoo 2010; Steele, Maruyama and Glaynker 2010) and are in evident need of intervention. Through increase in the wellbeing and resilience and improving coping styles, these negative effects of the role can be reduced whilst positive and protective factors can be instilled.

The feasibility data from the study reflect the difficulty of participant recruitment but show promising results in relation to participant retention, with regards to the complexity and length of the intervention piloting phase. Psychoeducation was rated as the most useful, meaningful and conducive to healthy changes in behaviours by participants, illustrating the benefit of such a component. The cognitive behavioural and social skills components scored well and equivocally, indicating the affinity for such methods by the caregivers. Mindfulness scored lowest, although still highly, of all components and further iterates the efforts required to increase the acceptableness of such an intervention approach.

Through the robust and informed development and evaluation of intervention assistance, it has been shown that those who care for relatives with BD can benefit from self-care. Future caregiver studies should recognise the potential of multi-component interventions over simple interventions to elicit the most benefit possible. The study shows that recruitment of participants is difficult but retention may be facilitated by interventions informed by lived experience. Participant recruitment may require a more dynamic and personal approach than a reliance upon gatekeepers at carer-likely locations.

7.7 Recommendations

7.7.1 Implications for Practice

Healthcare workers who engage either directly or indirectly with patient’s families should recognise the benefits of caregiver interventions which improve the health and wellbeing of not only the caregiver, but also the care receiver. Such benefits diminish the reliance upon healthcare services from both parties resulting in lowered costs and strain upon said services.

The high levels of effectiveness and acceptability coupled with the expressed need of interviewed participants for available and trustworthy sources, suggest a need for such a resource, or increased publication of existing sources. Those working in the community with family contact or those with family touch points providing care to BD patients should actively advocate resources.

Healthcare workers should also consider congruency and transparency when dealing with caregivers. Stage One showed a far greater trust and adherence to medical treatments when caregivers felt that they understood the process and were being included. The increased communication between caregivers and receivers reported from Stage Three also reflect the benefits of open communication.

7.7.2 Implications for Policy

This study showed how self-care can influence the health and wellbeing of those caring for a relative with BD. The intervention made changes subjectively, i.e. to coping, understanding, behaviours, and not to objective factors such as hours spent caring, or types of caring tasks. In this regard, policy holders should consider the cost-effective delivery of self-care intervention assistance to enhance the health and wellbeing of caregivers. Objective intervention assistance can be more costly in relation to practitioners, resources and time (Brouwer et al. 1999), where self-care can provide benefit as a precursor to future interpersonal assistance to alleviate the negative effects of the caregiving role.

7.7.3 Implications for further Health and Social Care Research

The phenomenon of Being Bound is a novel and important aspect of the experiences of those caring for a relative with BD. The paradox instilled between finding space for oneself and ensuring the health of their relative, whilst avoiding distress or guilt, could play a large role in understanding how and when caregivers are likely to seek, utilise and adhere to assistance. If the caregivers feel that their relative is being cared for, and do not experience the guilt or anxiety of not being the one providing this care, both respite for their relative and themselves could become more likely.

As the mindfulness component was rated the lowest regarding acceptability and meaningfulness with the lowest completion rate, further research in to the methods of delivering mindfulness to caregivers may show benefits for health and wellbeing. Enhancing mindfulness in caregivers may also provide an answer to the Being Bound dilemma where caregivers can use the techniques practiced in mindfulness to create a sense of their own space, without distancing themselves from the one they provide care for.

7.8 Conclusion

Providing care for a relative with BD is a complex and challenging experience but the negative consequences of the role can be addressed through adherence to self-care intervention methods leading to not just an improvement in health, but also wellbeing. A multi-component intervention of this nature for the caregivers of persons with BD has not previously been conducted. This study provides data from a robust and effective intervention following guidelines and proposals from caregiver intervention research and MRC guidance. The phenomenological research findings of Stage One are unique through the methods used to elicit them and provide a comprehensive display of the lived experiences of the population studied. These novel findings provide a deeper insight in to the experiences of caring for a relative with BD and informed the robust design of the intervention. Stage Three of the study resulted in positive indications for all components of the intervention to varying degrees, and provides feasibility data to facilitate future, large scale attempts.

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APPENDICES

Appendix One: Stage One Information Sheet

The development and external pilot of a controlled evaluation of a self care intervention to enhance the health and well-being of informal caregivers of relatives with bipolar disorder.

Dear Sir/Madam,
Thank you for your interest in the present study. I would very much appreciate the opportunity to talk to you about your experiences as a person who cares for a relative with bipolar disorder. Please take the time to read the following information and if you would like to take part or have any questions or queries please contact me by telephone, e-mail or letter.
Thank you for taking the time to reading this.

Regards,
Lee Boag

Research Team
Mr Lee Boag
Dr Mary Addo
Dr Colin Macduff
Dr Susan Klein

What is the purpose of the study?
The study aims to create a self-care intervention for those who provide support for a relative with bipolar disorder, within their own home. By doing so, negative or challenging aspects of the role should be reduced and positive aspects should be increased and maintained. To best understand where the difficulties, challenges and positive aspects of caring for someone with bipolar disorder arise we want to hear from people in this position, rather than making assumptions of the role or hearing it from indirect sources. We would greatly appreciate if we could hear these from you.

Do I have to take part?
No, your participation is entirely voluntary and it is your decision if you take part. You can withdraw for the interview at any time, and without reason. This includes any time after the interview has taken place.

What will happen if I take part?
We would like you to take part in a one to one interview, lasting approximately 45 minutes. The venue for the interview is your choice and can be in your own home, a private room at a carers' centre or we can organise a room within the Robert Gordon University. You will be interviewed by Lee Boag, the PhD student involved in the study.
At the interview you will be asked general personal information, such as age and occupation, and questions about your thoughts and views of the experiences you have had caring for your relative with bipolar disorder. You are free to not answer any questions and can stop the interview at any time. We will ask consent for the interview to be recorded using a voice recorder; however, you can stop the recording at any time.
Upon completion of the whole study, you will have the opportunity to receive information regarding the findings of the study that you will have contributed to.

Will my information be kept confidential?
Yes, all data will be held securely and will be kept confidential in accordance with the Data Protection Act 1998. The recordings of the interview will be transcribed by Lee Boag where your data will be anonymised and the audio recording will be deleted. Anything you tell us will only be used without your or your relative's names.
We are, however, obligated to report criminal activities to the appropriate authorities.

What might I not like about taking part?
It may be possible that talking about your experience could be upsetting. If this occurs, you can stop the interview at any time. After the interview, we will provide you with information regarding your local services for carers who provide services regarding information, support, advocacy and counselling – should you wish to make use of them.

What will happen to the results of the research study?
The findings of the interviews will create the basis of a self-care intervention for informal carers of relatives with bipolar disorder. The study will constitute a PhD and the findings will be publicised in research

articles and conferences. We hope that the study will improve the lives of those who care for a relative with bipolar disorder and better inform healthcare professionals with how to do this.

Who has checked this study?

The study has undergone ethical approval from the School of Nursing and Midwifery Ethics Review Panel.

Contact Information:
Mr Lee Boag
H313
Aberdeen Centre for Trauma Research
Institute for Health & Welfare
Garthdee Campus, Garthdee Road
AB10 7QJ
(01224) 263 101 1113729@rgu.ac.uk

Appendix Two: Stage One Consent Form

ROBERT GORDON UNIVERSITY•ABERDEEN

The development and external pilot of a controlled evaluation of a self care intervention to enhance the health and well-being of informal caregivers of relatives with bipolar disorder.

Consent Form

Please Initial Boxes

1. I confirm that I have read and understand the information sheet for the study titled above. I have had the opportunity to consider the information, ask any questions and have had these questions answered to my satisfaction. ☐
2. I understand that my participation in this study is voluntary and that I am free to withdraw at any time without stating a reason. ☐
3. I understand that data collected before and after the intervention will be looked at by the members of the research project and that my data will be kept confidential. I give my permission for these individuals to have access to this data. ☐
4. I agree to take part in the above study ☐

Name of participant: ....
Date:
Signature: ....
Name of researcher: ......Lee Boag................................
Date:
Signature: ....

Appendix Three: Stage One Debrief Sheet

ROBERT GORDON
UNIVERSITY•ABERDEEN

The development and external pilot of a controlled evaluation of a self care intervention to enhance the health and well-being of informal caregivers of relatives with bipolar disorder.

Debrief Sheet

Thank you for your participation in the study.
If you have any questions following your participation, please ask. If you think of something later, feel free to contact Lee Boag – contact details given below.

Having shared your experience you have made it possible for us to proceed to develop a self care intervention for those in a similar position to yourself: caring for a relative with bipolar disorder, that is rooted in the real lived experience of people. It is thought that providing self care will be more beneficial when an intervention is made that makes no assumptions of the role and developed from the experiences of those in the role.

Once the study is completed you will have the opportunity to have the information taken from the study sent to you for your own interest.

If, for any reason, you feel upset, confused or just want someone to talk to about the informal caring role, the local organisations below are aware of the study, what it entails and will be happy to provide you with support. There is also information available via a telephone service for carers and from the local council.
Thank you again for your participation, we greatly appreciate your time and input.

Study Contact Information
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Local Organisations

Aberdeen City VSA Carers' Services
Aberdeen City
38 Castle Street, Aberdeen AB11 5YU
01224 212021, carers.info@vsa.org.uk
Third Level Foundation
Aberdeen City
35A Union Street, Aberdeen, AB11 5BN
0800 021 7704, info@thirdlevelfoundation.co.uk

Telephone Based Organisations

Carers Direct – 0808 820 02 02

HealthPoints

HealthPoints offer free confidential health advice on practical ways to improve your health, access support groups and organisations, how to access NHS information and information about health conditions.
They can be found at:
Aberdeen Royal Infirmary, Concourse.
Aberdeen Indoor Market (In shops)
Dr Gray's Hospital, Elgin
The Hotspot, 1-3 Kirk Street, Peterhead.

Local Council

May provide services to help the person you care for, such as personal care and specialist equipment.

They can also help you get breaks from your caring tasks such as short breaks and respite.

They can check your eligibility for a Carers Assessment that looks at what your needs are as a carer. The council social work department can give you more information.

Aberdeen City Council – 01224 764 220
www.aberdeencity.gov.uk

Aberdeenshire Council – 0845 840 0070
www.aberdeenshire.gov.uk

Appendix Four: Stage One interview prompts.

Sociodemographic Information

Sex:
Age:
Ethnic Origin:
Employment: (Hours worked rather than job title)
Highest Educational Level:
Marital Status:
Who in House:
Relationship with CD:
Age of CD:

Areas to explore

Typology of Care Provided
Objective
Hours spent per day/week
Types of care provided (Social, Physical, Personal, Financial, and Psychological)

Relationship
Relationship with CD before/ after onset of BD?
How long they have acted as IC.
What concerns them the most about CD?
What their understanding of nature, causes and outcomes of BD?

Experiences of Role
How/ What things have changed?
Which aspects of the role do they feel are more positive?
Which aspects do they feel are less positive?
What would they like to change? - How do they think these things could happen? (Intervention)

Coping
Does role interfere with your other roles and responsibilities? – explore these.
What do they do to cope?
What helps them feel better?
What have they tried in the past – What worked and didn’t?

Support
Have they used professional assistance before?
Are other family/friends members involved?
Personal views of how support is/ should be. – do they feel they have enough.
How has healthcare system helped/ hindered?

Conclusion
Any issue covered want to elaborate?
Any issue not covered?

Appendix Five: Individual interpretations for each participant

Julia Participant No. 1 **Interpretation**

Julia, aged sixty, has been providing care for her husband for almost twenty years when he first became ill. This experience left her feeling like she'd lost a great deal of her identity and had to sacrifice her hopes and desires to provide as high a level a support as she could. She still feels that the role is a twenty-four hour obligation and plays an integral role in her husband's life from basic functioning, such as waking up in the morning and eating meals, to dealing with repeating suicidal ideations that she finds both disturbing and painful to hear. Out with the home, Julia works several part time jobs that allow her the flexibility to sustain her continual provision of care.

With the acknowledgement that she is a carer, Julia treats her provision of care as a sense of duty and attempts to deal with the anxieties she faces by being as proactively organised as possible which ultimately leads to more anxiety. With an awareness of her husband's possible triggers, such as noise, too many people, dispute and change, leisure activities restrict what they can and cannot do and Julia openly admits to being resigned and accepting that things are as good as they are going to get.

Originally career focused, her own ambitions in the world of work were quelled when she had to take almost full responsibility for their children growing up, on top of a provision of dutiful care to her husband, and in doing so has lost the chances for the life that she and her husband had planned when he was well. Despite this, she admits that this is worth it if it means a high standard of care for her loved ones. Where Julia may not appear to long for the life she can no longer have, she grieves for the man she married as she feels her husband has changed so much that he no longer embodies the memories she has.

Having been originally against Electroconvulsive Therapy (ECT) for her husband she feels that it is a better alternative to no treatment however, concern grows as she feels that the ECT is less effective with each session and she has been told that her husband's medication dosage is at its maximum level and does not see how this can lead to any positive outcomes. Her view of the healthcare system is generally positive in regards to treatment for her husband but admits that she felt unsupported when he was first diagnosed. Throughout her experiences she made use of Cognitive Behavioural Therapy (CBT) strategies that she has been made aware of.

Within herself, Julia has recognised changes such as being a more mature, empathic and caring person but admits that she would trade these for her old life and husband back to the way she remembers. These personal changes have led to coping styles that are problem solving in nature which seem to be effective in ensuring a running of routine and avoiding the triggers of her husband's condition. Julia has found peer support, routine and looking after herself to be of optimal benefit in alleviating the loneliness and anxiety that she experiences.

Constitutive Patterns

Loss of identity is lived as no longer being able to follow her chosen career path having given up her profession to have enough time to take care of their children growing up and to take a portfolio of flexible part-time jobs that allow her to provide continual care for her husband. It is lived in having lost the parts of herself that she associated with activities that she no longer has the time for. It is lived as dedicating large amounts of her day to ensure the basic needs of her husband are met.

Grief is lived as the memory of the man she shared a lively romance with that she is reminded of when glimpses of his previous behaviours and personality come through. It is lived as a constant reminder of the life she feels she has lost and the gradual settling down to how things are now.

Sense of Duty is lived as the need to provide the highest possible care for her husband. It is lived through the compulsion she has to be there for her husband twenty-four hours a day. It is lived through the unease of not being by her husband’s side and the measurements she scrupulously puts in place to stay in contact and remain in contact in her absence. It is lived through distaste for commendation of what she does for her husband as she does not consider it a choice and therefore not praiseworthy.

Anxiety is lived as a continual sense of unease and uncertainty. It is lived as a constant anticipation of numerous possible outcomes for any activity involving her husband to avoid triggers of his condition. It is lived as the worry that electroconvulsive therapy and medication may not be enough to control the situation anymore. It is lived as the fear that a resistance to treatment would lead to her husband’s death.

Coping is lived as an acceptance of her role as a carer. It is lived as acknowledgement that her life will not be the same but will only improve if she strives to do so. It is lived as problem solving regarding activities to avoid any impairment in her husband’s health. It is lived as introspection of her own actions and words to aide communication with her husband. It is lived as the sharing of experiences with those in similar situations that leave her feeling less frustrated and alone.

Suicidal Behaviours is lived as struggle to understand her husband’s ideations of killing himself. It is lived as the worry of something happening to trigger suicidal behaviours. It is lived as the uncertainty of what to do and say when her husband tells her that he wants to kill himself.

Strength of Care Recipient is lived as the pride and admiration she gains from seeing her husband try new treatments, changing his lifestyle and trying to cope with his illness. It is lived in appreciating when he is well enough to have cooked a meal for her.

Personal Growth is lived as the realisation of having changed as a person. It is lived as a strengthened empathy for others. It is lived as an understanding for how to respond to people who are distressed or vulnerable.

Violet Participant No. 2 **Interpretation**

For Violet, the role of carer for her husband has affected her both physically and mentally. Now the age of fifty-three, Violet has lived with chronic physical ill health for more than a decade. She feels that her potential physical recovery has been sacrificed through the strains and stresses that she has endured as a carer. Unable to work, Violet spent a great deal of continual contact with her husband and faced manic episodes from her husband that both frightened and endangered her whilst straining her emotional resilience.

The point of diagnosis for her husband came after these events whilst Violet tried to make sense and deal with these radical behaviours. In not knowing what she was up against, she experienced great deals of stress, isolation and frustration whilst attempting to find ways to cope. Violet felt unsupported by the healthcare system at this time and reports lack of cooperation and communication in her dealings with staff leaving her questioning her own sanity at the time.

As time progressed and her husband received treatment, Violet felt that efforts to make her husband well were hollow and misdirected. In her experiences with her husband, she feels that she has a level of understanding that could greatly assist with her husband's care but does not feel listened to. Not all of Violet's experiences in dealing with the healthcare system have been negative, she recalls when her husband was circumstantially admitted to a different hospital to the one they normally attended with which she described as being "very good and [having] a modern way of treatment." but was shortly admitted back.

Violet came in to contact with her local carer's group and was shocked to find out about her entitlement to a Carer's Needs Assessment and that one had not been done. The results of the assessment assisted Violet a great deal and founded her trust with the carer's group. Becoming more aware of her rights she sought advocacy and has kept audit trails of all her communications with hospital staff in an effort to make her voice heard with the aim of ensuring that a duty of care was upheld for both her husband and herself.

A relationship with her husband has been hard to maintain as Violet feels like a barrier sits between them that she can't communicate through. She feels that bipolar disorder has taken over her husband and attributes his behaviours to the condition, rather than the person. This distinction helps Violet carry on by not taking offences personally makes her more adamant to have her husband treated the way she feels he should be so she can have him back.

Violet pre-empts mood states through awareness of triggers and tells such as going to bed late or housework going undone. These signs allow her to prepare for mood changes that she feels that she is managing to get the hang of. Whilst receiving treatment for her own illness she was provided with a course of therapy in which she feels that she gained the insights and tools to cope in her role as carer, such as reflection and transactional analysis.

Constitutive Patterns

Exhaustion is lived as being with her husband twenty four hours a day as her own illness limits how and where she can go. It is lived as trying to understand and alleviate her husband's symptoms without a diagnosis for a long period of time. It is lived as the emotional strain of trying not to take her husband's actions to heart.

Frustration is lived as feeling like no one listens to her despite her best intentions and efforts. It is lived as being unable to rationally talk to her husband to try and help. It is lived as wanting what she believes as a high standard of care for her husband and feeling that it is not being provided.

Physical Pain is lived as the lack of recovery made in her own physical health due to the consequences of her role as carer. It is lived as the repercussive pain of visiting her husband in hospital. It is lived as having no alternative mobility transport available and having to make use of a standard car for essential tasks, despite physical detriment, for years before a carer's assessment was made.

Isolation is lived as not being told about her husband's treatment or illness at diagnosis. It is lived as living with a man that she feels has put an emotional wall between them despite having been close in the past. It is lived as feeling ignored by some of those she has sought help and assistance from.

Coping is lived as learning the patterns and behaviours of her husband to predict mood changes and ready for them. It is lived as attributing her husband's behaviours to his condition and not to him so that she may deal with things that would have previously hurt her in a more objective way. It is lived as creating an audit trail and contacting any authority she can to see done what she wants to happen. It is lived as the self awareness she has developed to ensure her interactions with her husband are congruent and open.

Challenging Behaviours is lived as experiencing behaviours that caused a medley of distress, betrayal, frustration and exhaustion. It is lived as feeling unwelcome in her own home when the man she lives with seems nothing like her husband.

Safety of Care Recipient is lived as the knowledge that she has done right by her husband. It is lived as the belief that without her and the support she provides that her husband would be either deceased or in prison.

Elaine Participant No. 3 **Interpretation**

A retired healthcare worker, at seventy one years old, Elaine was always certain she wanted to work in a job where she could help others. However, Elaine hadn't anticipated that she would become a carer for her husband and has been in this role for over thirty years. Upon diagnosis of bipolar disorder, Elaine and her husband sold their home and business in an effort to get away from the stresses that seemed to have triggered the onset of Bipolar Disorder and settled in a more isolated rural setting.

Elaine admits that the location is not where she would have liked to stay and having always been very proactive and social she experienced high levels of stress which didn't really waver for at least two years after the diagnosis. Adjusting to the new environment was difficult for Elaine but she held the health of her husband as a higher priority and has slowly been regaining her identity back. She has joined a small carer's group close to where she stays and both she and her husband involve themselves in different groups and social activities to keep them occupied throughout the week.

The lifestyle that they live is markedly different from when her husband was first diagnosed where Elaine describes their relationship as "Ships passing in the night." due to alternating work schedules and shared responsibility over their children. Elaine feels that sustaining this level of sporadic contact led her to miss signs and pre-cursors of her husband's mental health that retrospectively are indicative. She also admits that her husband was never very open about his feelings but still carries a great deal of guilt that she was unaware of such an important aspect of a loved one's life.

Feeling that when her husband took ill was the worst day of her life, Elaine was initially unprepared for the role of carer and was drastically taken aback at expressions of suicidal thoughts. She recalls watching him all the time to be sure he was okay but as time progressed she and her husband communicated more about his mental health which alleviated some of her fears but a constant concern that he may one day take his own life is something that still sits in the back of her mind.

Her husband would not have been so open with her before, and even though it may not always be positive emotions he is sharing, Elaine seems to appreciate a strengthening of aspects of their relationship that may not have existed. Elaine fully accepted the role of carer for her husband and admits that it is a twenty four hour a day obligation. Assisting with day to day tasks, Elaine is always vigilant of changes in mood and spends a lot of time reminding her husband of tasks he must do as she has identified the incompletion of obligations as a trigger of his mental health.

Elaine is proud of the support she has provided her husband over the years and derives a sense of satisfaction for being there for him but can't seem to let go of the guilt she has carried with her for so long in regards to not having known her husband had bipolar disorder.

Constitutive Patterns

Loss of Identity is lived as having moved away from a routine and, consequently, a sense of identity and purpose so that she and her husband could avoid stressors and possible triggers for his illness. It is lived as the feelings of lose and isolation as she tried to build a new life up after having realised that her old life no longer existed.

Stress is lived as the amalgamation of worries and surprise surrounding her husband's health and how she felt so awestruck at point of diagnosis that she did not know what to do. It is lived as a two year period of her life in which she felt unable to cope with the demands of the new role and was referred to a doctor's surgery with resultant angina.

Anxiety is lived as the continual assessment of her husband's mood and the thought that he may potentially commit suicide some day. It is lived in not knowing how he would cope on his own if something were to happen to her.

Guilt is lived as an on going remorse for not having recognised that her husband was ill. It is lived as always wondering if she had tried to talk with him more often or spent more time together as a family that help could have been provided for him sooner.

Coping is the construction of a new sense of self through purposeful activities and a routine of leisure activities. It is lived as the support from peer groups in which she feels understood by those who have experience the same. It is lived through an awareness of her husband's triggers so that she may remain with a sense of control over situations.

Meaning through Caregiving is lived through a continuation of the personal beliefs and values that encouraged Elaine to work in the healthcare sector initially. It is lived as a sense of satisfaction that she has done well by her husband and that her support contributes very much to his well-being.

Bound to Care Recipient's Location is lived through initially being so afraid at the diagnosis of bipolar disorder that she watched her husband every waking moment. It is lived through finding it difficult to go anywhere without him or not know where is and what he is doing due to her lasting fear that he may commit suicide is always at the back of Elaine's mind.

Suicidal Behaviours is lived as the shock when her husband tells her that he wants to leave the life the have together. It is lived as an unerring concern that he could commit suicide at any time and she may not be able to stop him.

Donna Participant No. 4 **Interpretation**

Donna is the mother of a young woman who was diagnosed with Bipolar Disorder within the past year. In her seventies, Donna lives with her husband Tim (Participant 5.) and provides care for her daughter who lives with two children. Donna feels that things have become enormously better since her daughter was diagnosed and began receiving medication for her condition. Donna is in frequent contact with her daughter throughout each day to provide a level of emotional support. Her daughter's condition meant that a great deal of looking after her children rested upon the shoulders of Donna and Tim and Donna notes how she does not feel her daughter would survive financially without their assistance.

It has been difficult for Donna to be so close with her Grandchildren whilst trying to strike a balance in the role she plays as not to take over the role of their Mother as she feels this would be an emotional betrayal to her daughter. Tasks like shopping are still difficult for her daughter and Donna regularly accompanies her for emotional support for such things. She describes their relationship as closer now but can still recall the challenging behaviours that existed not too long ago prior to diagnosis and medication.

Endless rows and having her daughter blame her for everything was very common experiences for Donna. She found the way her daughter reacted to her very upsetting and difficult to deal with. Donna felt frustrated with not knowing how to cope and with the lack of advice and support they were receiving prior to her daughter's diagnosis. Over time, this frustration led to anger and Donna felt like she was constantly walking on egg shells to avoid "explosions" of emotion that could lead to her daughter leaving the house and not returning for substantial periods of time.

Whilst her daughter's behaviours could be impulsive, they also seemed to be aimed at dividing Donna and Tim. Donna felt isolated and that her husband had taken her daughter's side which coupled with arguments from her daughter personally aimed at her left Donna feeling hurt and unsure what to. She recalls this as the most difficult period of her experience but describes how she and Tim learned to talk to one another and stand together to try and help their daughter which made a substantial positive difference to how she had felt.

Donna pays credence to the skills she developed in her working life, where she had to know how to communicate with others and posses a degree of self awareness, in how she managed to cope. Being able to talk tactfully, display empathy and monitor her own reactions helped Donna mediate some situations which may have escalated further. Seeing her daughter now coping with her condition fills Donna with a sense of admiration and she commends her daughter's progress and admits that this admiration makes her a lot more patient whereas before she was merely trying to handle numerous situations.

In contrast to her daughter's earlier behaviour, Donna is grateful for the help her daughter has received but feels that she has been unsupported throughout her own experiences. She is also grateful to her other daughter who she feels has been great source of support to the family

Constitutive Patterns

Family Responsibilities is lived as providing more care to her Grandchildren that would have otherwise been expected. It is lived as trying not to take the place of the children's Mother despite feeling very close to them

Financial Support is lived as providing monetary assistance when her daughter's behaviours focus on spending what she doesn't have. It is lived in providing basic essentials for her daughter and her children when they don't have enough to live on due to the repercussions of manic episodes.

Challenging Behaviours is lived as being a target for torrents of arguments and blame from her daughter. It is lived as constantly trying to keep the peace to avoid her daughter disappearing for days. It is lived as trying to stand as a united front with her husband and not be played off against one another.

Support from Others is lived as her other daughter being there to discuss things with and provide a level of companionship through times when she felt that things were getting too much.

Isolation is lived as feeling that her husband was not supporting her and her daughter was against her. It is lived as the anger and frustration at trying to deal with things but being victimised and blamed for things that weren't her fault.

Helplessness is lived as not knowing what to do to cope and what to do to help her daughter. It is lived as the lack of support she felt due to her daughter now having a diagnosis and thus no clear way to deal with things.

Coping is lived through the self awareness to mediate her own behaviours and empathy to talk in a tactful and assuring way to her daughter to deescalate possible situations with her daughter. It is lived as learning to communicate with her husband so that they can support each other and provide a sense of united control in the face of experienced challenging behaviours from her daughter.

Strength of Care Recipient is lived as the pride she has for her daughter in regards to the strength she has displayed in overcoming her illness now that they have a diagnosis. It is lived as the patience she has developed in light of this as the determination displayed by her daughter lets her see how much she is trying to get better.

Tim Participant No. 5 **Interpretation**

Tim, husband of Donna (Participant 4), shares the same level of relief following diagnosis and treatment for his daughter. The retired seventy four year old recognises a big difference in the behaviours of his daughter and the resulting care that he and his wife provide to counteract these. Fully thankful to the medication regime, Tim feels that it is solely responsible for the improvements in his daughters health compared to the past fifteen years when he says her 'troubles began'.

Retrospectively, he details his daughter's behaviour as consisting of endless rows, potential violent outbursts and disappearing for days at a time which led him to feel apprehensive in her presence and unsure how to help. Tim felt great deals of frustration when he would help his daughter clean her house and it would be dirty again within a few days due to her impulsive collecting of animals. He feels that she is very dependant financially and would not be able to cope on her own even though she has become better at controlling her spending, but not by enough.

In the fifteen years before diagnosis, Tim felt unsupported and helpless and reports that when he reached out for support or assurance to healthcare professionals that they did not help. He feels that having a diagnosis allows him to understand that she is ill and that things are contained up to a point which things less challenging. His understanding of the illness also makes him less resentful when having to provide care in areas that he would have otherwise felt that she was more than capable of doing herself.

Prior to Tim's retirement and his daughter's diagnosis, Tim's job would take him away from home throughout the week and he would dread coming home to be met with recanted stories from both sides of his wife and daughter in which he felt he was put in the middle of things. This led Tim to feel a level of anxiety in trying to strike a balance between being sympathetic and supportive to both sides.

Tim still feels that he and his wife still play a major role in looking after their grandchildren and recognises a strong connection with them. He feels that one of his grandchildren is of a great continual support to her Mother and feels a sense of relief to know that there are others in the family that he can count on to be able to provide support.

Tim feels that he began to learn how to cope when he could understand his daughter as having an illness and that this allowed him to be cautious and to not expect her reactions to be those of a healthy person. This distinction allowed Tim to take things less personally before and helped him manage behaviours more easily.

Despite feeling that things have improved, Tim still feels very restricted in what he wants to do. He admits that he would rather live somewhere else, have more trips away and lacks a sense of freedom that he longed for in retirement. In response to this, Tim emphasises the importance of having your own space and time do things to provide him an opportunity for feeling content and attended to for a change.

Constitutive Patterns

Family Responsibilities is lived as the support he provides his grandchildren to help his daughter cope with the responsibility.

Financial Support is lived as supporting his daughter by paying for incurred debts and buying basic essentials for his daughter and her family.

Challenging Behaviours is lived as having to be cautious and wary of his daughter due to unpredictable and sometimes inevitable displays of anger and potential violence. It is lived as the consequences of his daughter disappearing for a few times at a time and the level of guilt and worry he felt till she came back. It is lived as feeling the he is torn between being supportive towards his wife without triggering a negative response in his daughter.

Support from Others is lived as the acknowledgement that his granddaughter is learning to be a great support to her Mother. It is lived as a slight relief to know that there are other people who are trying, and seem capable, of helping his daughter.

Coping is lived as learning to not take things personally and accept that not all things his daughter does and says are meant to cause him hurt. It is lived as not expecting clear and predictable reactions from his daughter and being less resentful in light of his differentiation between the condition and the daughter he feels is capable of looking after herself.

Anxiety is lived as the unerring worry whiles away from home and not knowing what he was going home to. It is lived as feeling stuck in the middle and being unsure how to react to those he loved for fear of hurting anyone.

Frustration is lived as fifteen years of tirelessly trying to understand and deal with symptoms of something that was neither recognised not accepted by his daughter. It is lived as wanting things to change but knowing how or who to turn to.

Harry is a forty-eight your old self employed gardener who cares for his wife with bipolar disorder. He feels that he would rather have the stability of working for a company but his current job allows him the flexibility to increase his provision of care for his wife when she needs it. He can feel quite anxious when he is not with her and calls her from work during the day to see how she is and provide emotional support if necessary.

Harry recognises his role as a twenty four hour obligation and tries to instil a sense of routine with his wife's day so that it can be easier for her to know what to do. He finds the depressive mood episodes the hardest to deal with and feels a great deal of guilt in admitting that it can be like his wife disappears and he finds it harder to carry on when he can't see the person he loves and can feel unappreciated when this happens.

Providing care is not a choice for Harry and he knows that his wife would do the same for him but feels that she may have done a better job than he can because she was more patient and kind. He sometimes questions himself and his ability to care for his wife as to whether he is doing the best for her that he can. It is this self-doubt and not wanting to be judged after trying so hard that stops Harry from looking for peer support as he is afraid that he has been doing 'the wrong things' for so long that it would hurt him to think his best efforts weren't enough.

Harry feels he struggles the most with his wife's lack of communication when she is low and the risk of suicide attempts. The potential for his wife to attempt suicide is what makes Harry so anxious when he is away from his wife that he prefers not to go out without her despite once having an active social life for himself. He feels that this has led to an old part of himself having faded away and worries that he cannot share this with his wife as he does not want guilt to be a trigger for a mood episode.

Pre-empting what can cause dips in his wife's mood allow him to counteract these with activities that produce positive results such as contact with their children, trips outside and stronger routine. In understanding what can improve his wife's mood, Harry feels he is giving the best care he can and appreciates a sense of trust that has developed between the two of them since he took over the caring role.

In providing care for his wife, Harry is ensuring that he feels that she is looked after well although he experiences a lot of anxiety through second guessing his own efforts. He feels closer to his wife in some ways but acknowledges that things are different and he has lost part of himself in the process. The journey so far has left Harry feeling alone at times and he still finds his wife's behaviours to be concerning and confusing.

Constitutive Patterns

Sense of Duty is lived as feeling that there was no choice in taking on the role of carer for his wife. It is lived as the obligation he feels to provide the best level of care he possibly can.

Guilt is lived as sometimes feeling like the woman he loves is lost somewhere in the condition. It is lived as retrospectively feeling bad for resenting his wife more when she seems less appreciative of his efforts.

Anxiety is lived as constantly second guessing the care he provides. It is lived in being so worried that his best is simply not good enough and the concern that other people would judge his efforts.

Challenging Behaviours is lived as trying to communicate with his wife when she is in a low mood state and not being able to help. It is lived as the lack of response he can get despite trying the things that normally work and not knowing why they won't elicit a response this time.

Suicidal Behaviours is lived as the constant worry that his wife may end her own life. It is lived as the bewilderment of how she can feel that way and the shock of someone being so blunt about something he had never come in to contact before.

Isolation is lived as the feeling of being on his own against his wife's illness and not having the things in his life that meant he associated with other people. It is lived in the longing for his wife's mood to increase to where he can feel like he is living with another person in the house he can talk to and interact with.

Loss of Identity is lived as no longer having the time, or desire, to do the things that once made him happy and defined who he was. It is lived in being a new person in a new role that he does not fully understand, and therefore, not fully understand himself.

Coping is lived in trying pre-empt mood states and knowing which things can improve his wife's moods so that he can increase the frequency of these things when needed.

Safety for Care Recipient is lived through the acknowledgement of his role as being able to provide a higher standard of care than what he views the alternatives for her care to be. It is lived as knowing that his wife has someone looking after her who has her best interests at heart.

Appendix Six: Stage Three Information Sheet

The development and external pilot of a controlled evaluation of a self care intervention to enhance the health and well-being of informal caregivers of relatives with bipolar disorder.

Dear Sir/Madam,
Thank you for your interest in the present study. I would very much appreciate your participation in this present study which aims at finding out how to better assist those in your situation – caring for a relative or partner with bipolar disorder. The study would involve you participating in an intervention which has four parts, all of which are thought to help and assist people in different ways. I am interested to see how effective these methods are and for whom. Please take the time to read the following information and if you would like to take part or have any questions or queries please contact me by telephone, e-mail or letter.
Thank you for taking the time to reading this.

Regards,
Lee Boag

Research Team

Mr Lee Boag
Dr Mary Addo
Professor Susan Klein
Dr John Love

What is the purpose of the study?

The study aims to better understand how to assist those who provide support for a relative with bipolar disorder. This will be achieved by providing informal caregivers a self-care intervention – information and different ways to help with your role. The intervention has four different booklets with different ways of offering this assistance through your own participation. By understanding how helpful and to whom these methods of helping are, we can make sure that those in the same role as you receive help that is most effective and beneficial to them.

Do I have to take part?

No, your participation is entirely voluntary and it is your decision if you take part. You can withdraw from the study at any time, and without reason. This includes any time after the intervention has taken place.

What will happen if I take part?

Before the intervention you will be given a booklet of questions to let us see what things are like just now. When you complete this you will receive the self-care intervention as booklets for you to work through. You will be given 4 months to do this at your own pace. After the 4 months, we will ask you the same questions as we did at the start to see what has changed. You will also be asked to give your opinion about any changes, how you felt about the intervention and what you liked/disliked about it. The intervention is not meant to replace any treatments or help you may be receiving.

Will my information be kept confidential?

Yes, all data will be held securely, will be anonymised and kept confidential in accordance with the Data Protection Act 1998.

What will happen to the results of the research study?

The results will help us better understand the situation of providing care to a family member with bipolar disorder. Changes in how people feel and respond to questions before and after the intervention will inform us on which methods of helping people are useful and who they are useful for. The research will help provide information to make sure that care givers are provided with the best possible support in the most effective way.

Who has checked this study?

The study has undergone ethical approval from the School of Nursing and Midwifery Ethics Review Panel.

Contact Information:
Mr Lee Boag
H313
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Institute for Health & Welfare
Garthdee Campus, Garthdee Road
AB10 7QJ
(01224) 263 101 l.s.boag@rgu.ac.uk

Appendix Seven: Stage Three Consent Form

ROBERT GORDON
UNIVERSITY ABERDEEN

The development and external pilot of a controlled evaluation of a self care intervention to enhance the health and well-being of informal caregivers of relatives with bipolar disorder.

Consent Form

Please Initial Boxes

I confirm that I have read and understand the information sheet for the study titled above. I have had the opportunity to consider the information, ask any questions and have had these questions answered to my satisfaction. ☐

I understand that my participation in this study is voluntary and that I am free to withdraw at any time without stating a reason. ☐

I understand that data collected before and after the intervention will be looked at by the members of the research project and that my data will be kept confidential. I give my permission for these individuals to have access to this data. ☐

I agree to take part in the above study ☐

Name of participant: ....
Date:
Signature: ....
Name of researcher: ......Lee Boag...............................
Date:
Signature: ....

Appendix Eight: Stage Three Debrief Letter

Dear *Name,*

Thank you very much for your participation in the research study. Your contribution will help us to better understand how to provide support and work with people in the caring role for those with Bipolar Disorder like yourself.

The same questionnaire booklet is enclosed as was last time and if you could now please fill this out for how things are now. There is also some other sheets regarding feedback you have about the intervention and your experience. Your feedback here allows us to see what your opinions, thoughts and feelings are in regards to the intervention.

Please send both of these sheets back to me in the pre-paid envelope you will also find enclosed. Your intervention booklet is yours to keep so you can make use of it again in the future if you would like to. Participation is still voluntary and if you so chose, you can leave the study without explanation.

I very much appreciate the time and effort you have put in to take part in this study. If you have any questions at all, please feel free to contact me at any time.

Best regards,

Lee Boag

Appendix Nine: Gannt Chart Outlining Three Year Process of Project

	10/11	**11/11**	**12/11**	**1/12**	**2/12**	**3/12**	**4/12**	**5/12**	**6/12**	**7/12**	**8/12**	**9/12**
Literature Search	**X**	**X**	**X**		**X**	**X**				**X**	**X**	
Gather Literature			**X**	**X**		**X**					**X**	**X**
Review Literature			**X**	**X**		**X**						**X**
PGCert 1		**X**										
PGCert 2						**X**	**X**					
Nvivo Interviews							**X**	**X**				
Sort Qual. Data												
Develop Intervention											**X**	**X**
Baseline (1)												
Follow Up (2)												
Follow Up (3)												
Ethical Approval					**X**							
Conferences							**X**				**x**	**x**
Analysis								**X**	**X**			
Writing Up									**X**	**X**		
Submit Thesis												
Viva												
Submit Final Thesis												

	10/12	**11/12**	**12/12**	**1/13**	**2/13**	**3/13**	**4/13**	**5/13**	**6/13**	**7/13**	**8/13**	**9/13**
Literature Search					**X**					**X**	**X**	
Gather Literature					**X**					**X**	**X**	
Review Literature	**X**	**X**			**X**	**X**				**X**	**X**	**X**
PGCert 1												
PGCert 2	**X**											
Nvivo Interviews												
Sort Qual. Data												
Develop Intervention	**X**	**X**	**x**									
Baseline (1)				**X**	**x**	**X**						
Follow Up (2)								**X**	**X**	**x**	**x**	
Follow Up (3)												
Ethical Approval												
Conferences						**X**	**x**					
Analysis		**X**			**X**				**X**	**X**		
Writing Up		**X**	**X**		**X**	**X**	**X**			**X**	**X**	**X**
Submit Thesis												
Viva												
Submit Final Thesis												

	10/13	**11/13**	**12/13**	**1/14**	**2/14**	**3/14**	**4/14**	**5/14**	**6/14**	**7/14**	**8/14**	**9/14**
Literature Search	X		X									
Gather Literature	X		X									
Review Literature	X	X	X									
PGCert 1												
PGCert 2												
Nvivo Interviews												
Sort Qual. Data												
Develop Intervention												
Baseline (1)												
Follow Up (2)												
Follow Up (3)	X	X										
Ethical Approval												
Conferences				X				X				
Analysis		X	X									
Writing Up			X	X	X	X	X		X	X	X	
Submit Thesis							X					
Viva								x	x			
Submit Final Thesis												X