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Investigation of Mindfulness, Psychological Inflexibility and Valued Living as Potential Moderators of the Relationships between Burden, Distress and Well-being in Unpaid Carers.

Lindsey Slowey

Doctorate in Clinical Psychology

The University of Edinburgh

2013
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Abstract

**Introduction:** Unpaid carers are known to be at heightened risk of poor outcomes (e.g. financially, physically and emotionally). Conversely it is known that carers can have positive experiences through their caring role and continue to experience good well-being even when distress is present. The study proposes that mindfulness, psychological inflexibility and valued living may moderate the relationship between distress and well-being in carers and therefore help ameliorate some of the potentially negative consequences of caring.

**Method:** 55 unpaid carers completed self-report measures of burden, distress mindfulness, valued living and psychological inflexibility. The results were analysed using correlation analysis and moderated multiple regressions.

**Results:** Psychological inflexibility and valued living were found to moderate the relationship between distress and well-being in carers. There was evidence of valued living having a moderating relationship between burden and well-being. Correlation analysis indicated that there were significant negative relationships between valued living, mindfulness and distress; and psychological inflexibility and well-being. In addition positive relationships were found between mindfulness, valued living and well-being; and psychological inflexibility and distress.

**Discussion:** The results of the study provide further support to the existing evidence base for mindfulness and ACT, which is the approach behind the concepts of valued living and psychological inflexibility. This suggests that mindfulness, valued living and psychological inflexibility should be explored further in carers. Recommendations for future research into the use of mindfulness and ACT for carers are discussed.
Chapter 1 - Introduction

1.1 General Introduction
There are approximately 657,300 informal carers within Scotland (Scottish Household Survey, 2008). Being an informal carer has been associated with a number of negative outcomes for the carer. These are evident in the domains of physical and psychological health (Pinquart & Sörensen, 2003).

The current evidence base for interventions for informal carers is mixed. While there appears to be some evidence that psycho-educational interventions are effective for carers (Gallagher-Thompson & Coon, 2007), overall the evidence-base for interventions to improve psychological functioning is poor. Overall there appears to be a lack of good quality studies in the area, which may be attributable to the lack of theory-based interventions (Parker et al., 2010)

A number of conceptual models have been developed to explain informal caregiver stress/negative outcomes; however there are a few limitations with these models. In particular, it has been highlighted that the models lack consideration of potential positive experiences associated with undertaking a caring role (Folkman, 1997). While in its infancy, research has suggested that these positive experiences are an important area for carers. It is hypothesised that positive experiences related to caring may be a protective factor against distress and there is some evidence for this (Folkman, 1997). Areas of positive outcome resultant to the caring role are likely to be linked to a person’s ability to find meaning in the role and their intrinsic motivation to take on the role. These factors could be theorised as being part of a person’s goals or value system.

The emerging evidence-base and popularity of Acceptance and Commitment Therapy (ACT) has lead to increased interest in values in recent years, though similar
concepts have previously existed. Values in ACT cover a number of different
domains and are seen as the general way in which an individual would like to live
their life. They are conceptually different from goals as values cannot be achieved
per se. Instead goals may be set which are in line with an individual’s values. Thus,
by virtue of achieving value-directed goals an individual lives in accordance with
their values. This value-directed living has been suggested to create greater well-
being. With regard to caring, it is suggested that if the caring role is in accordance
with someone’s existing values they may be less likely to experience negative
symptoms. However, with this experiential acceptance is also required as it is likely
that the caring role may still give rise to unpleasant experiences which may be met
with avoidance, further fuelling psychological distress (Hayes, 1999). Processes
such as acceptance and mindfulness (see sections 1.10 and 1.11) are therefore also
likely to be required to facilitate the individual’s experiential acceptance of both the
positive and negative aspects of the caring role.

This introduction aims to review carer outcomes, to explore and discuss existing
models of care-giving and propose that mindfulness, psychological inflexibility and
valued living may have a role in moderating carer distress and wellbeing.

1.2 Definition of Informal Carer
An informal carer is commonly defined as an individual who cares for another
person, who would not be able to complete their activities of daily living without the
care. An informal carer does not receive any payment for their role, though some
may be entitled to carer allowance. Voluntary workers within the care sector are not
included in the informal carer definition. The legal definition of a carer is “someone
who provides substantial amounts of care on a regular basis for either an adult or a
child, where that adult or child receives, or is eligible to receive, support services
under the Social Work (Scotland) Act 1968 or the Children (Scotland) Act 1995.”
(The Community Care and Health (Scotland) ACT, 2002).
The legal definition is used to determine carer allowance and the right for a carer’s assessment to be carried out and subsequent support to be given by Social Work. It has been argued that it is a stringent definition which neglects a number of carers, as not everyone who requires care will necessarily be eligible to receive Social Work services. The Scottish Executive (2006, p.4) defines an unpaid carer as ‘an individual who cares for a friend, relative or neighbour without receiving paid income in addition to income through the benefits system.’ It is this definition that will be used in the current study. This definition does not include young carers (individuals under 18 years of age who are providing care) as they are defined separately in legislation. In addition it only includes parents if they are providing care to their child beyond usual parenting duties. Parents are included as unpaid carers if they are required to provide additional care to a child whom is physically ill or who has a mental health diagnosis. In the current study no parent carers were recruited.

The definition used is quite wide and its choice is deliberate to try and ensure that carers in all circumstances are sampled. More stringent definitions could be used, such as the carer having to be in receipt of carer allowance. However, this would limit the sample as not all carers are entitled to it (e.g. if retired, earn over a threshold, care for less than 35 hours per week). It would also limit the comparability of the current study to other carer literature, which also tends to use a wider definition of unpaid carer. In addition, it was thought that it would be intrusive to request carers who indicated an interest in the study to prove that the person they care for was in receipt of/or eligible for Social Work support.

Informal carers typically care for a friend, relative or neighbour who, without their help, may not be able to live independently or complete essential activities of daily living (Scottish Executive, 2006). The type of people whom informal carers support is varied and could include people who have a chronic illness, mental health condition, are frail or disabled. Informal carers are also referred to as unpaid carers.
or family caregivers within the literature. Informal carers tend to prefer to refer to themselves as carers; therefore the term carer will refer to informal carers, unless stated elsewhere.

1.3 Prevalence of Caring
It is estimated that 12% of the UK population provides informal care (Buckner & Yeandle, 2011). Results from the 2009/2010 Scottish household survey indicate that 12.4% of the adult population provide informal care; this does not include carers under the age of 18 (The Scottish Government, 2011). The true number of informal carers may be greater as some informal carers do not identify themselves as caring for someone else and therefore are not counted in self-reported statistics. Often this is due to the carer believing they are just fulfilling the role and duties as a parent, spouse, child or sibling and do not recognise the caring role they are providing. In addition the Scottish Household Survey asks whether anyone in the household receives care. There could be instances when the care-recipient does not recognise themselves as receiving care from others, particularly family members, and therefore does not provide an answer that is a true reflection of the situation. It also only surveys individuals in private residences so may miss people who are in care homes or respite accommodation whom are receiving care by non-professionals some of the time.

1.4 Service Context
Interest in informal carers began to increase following the move from institution-based care to care in the community in the 1990s. The change in service provision made it more likely that family members would take on an active role in caring for their relatives. Other factors such as advances in medical treatments, which lead to increased life spans for those with chronic conditions and the aging population, increase the number of people who require care. With service decommissioning these people are likely to require more care in the community. As a result the need for informal care is predicted to continue to rise in the future (Pickard, 2008).
Economically, carers provide a vital role. A report by Carers UK and Leeds University estimates that carers are providing 119 billion pounds per year worth of care (Buckner & Yeandle, 2011). Therefore, annually, the provision of informal care saves the British Government a substantial amount of money. Realisation of the financial importance of carers has lead to the development of policies and strategies aiming to protect and support informal carers, as without them there would be even more demands on services and Government finances than there is currently.

In summary, it is estimated that at any given point 12% of the UK population are caring for an individual, though this number may be higher (Buckner & Yeandle, 2011). The caring role saves the UK government a substantial amount of money as carers take on the role that would normally have to be filled by paid carers.

1.5 Impact of Caring
This section presents evidence that taking on a caring role can be detrimental to the carer financially, physically and emotionally along with suggestions of why this may be the case.

1.5.1 Financial / Loss of Work
Research has indicated that financial difficulty can be a strong predictor of negative health and psychosocial outcomes (Robinson et al., 2009). Informal carers often have increased financial demands. A recent study identified that 315,000 carers in England had given up employment in order to undertake their caring role (Pickard et al., 2012). Other organisations, estimate this figure to be higher, at around 1 million, though they include carers who have had to reduce their hours due to their caring role, which would inflate the figure (Carers UK, 2011). In addition the higher estimates represent the whole of the UK, not just England.
Carers Allowance is a benefit provided by the UK Government to assist informal carers in their role, though only a small proportion of informal carers are entitled to it and it is estimated that only 65% of those entitled claim it (Berthoud, 2010). The benefit works out at below the minimum wage. Financial pressures can have an added impact on informal carers’ health with 47% reporting that this was the case, particularly with regard to stress, worry and depression (Carers UK, 2010). With the added financial pressure a high percentage of carers have had to cut back on extra activities such as holidays (78%), leisure (74%) and socialising (74%), (Carers UK, 2010). Some studies indicate respite and time to self are important protective factors against stress and burnout for informal carers (Ashworth & Baker, 2000). Having to reducesuch activities could therefore be potentially detrimental to informal carers’ health. While the Carers UK survey outlines some interesting findings, these should be interpreted with caution as it was a cross-sectional online questionnaire that was accessed through the Carers UK website and Carers UK is a support group which campaigns for carers. Therefore it is potentially a biased sample as carers who do not access the internet or use Carers UK would have been unable to complete the survey. The survey was also undertaken during 2008, which in the UK was a time of recession and there was no comparison to any cut backs non-carers may have been making at this time. A large number of carers did complete the study (N=1707), however details which are important in understanding the sample are unknown such as age, gender, length of time caring etc.

1.5.2 Physical Health
The Caregiver Health Effects Study (Schulz & Beach, 1999) found that informal carers who cared for their spouse and reported caregiver strain were 63% more likely to die within a four year period than non-caregivers. This sample involved informal carers who were caring for an adult over 65 years of age with cardiovascular disease. The non-caregiver sample was matched for age and gender. This study highlights a potential link between caregiver strain and poor health outcomes as only the informal carers who reported strain had the higher mortality rate (Schulz & Beach, 1999). However, it is difficult to determine whether it is the physical or the emotional strain, or both, that are important, as they are combined under ‘caregiving strain’.
Pinquart & Sörensen (2007) conducted a meta-analysis on correlates of caregiver health in informal carers of older adults. Their results indicated that the severity of the care-recipients’ behaviour and cognitive impairments, length of time in a caregiver role, co-residence, non-spousal caregiver, higher caregiver burden and depression, older age, lower SES and lower levels of informal support were all related to worse physical health in caregivers. This is in keeping with earlier research where informal caregivers were found to have poorer physical health than non-caregivers (Pinquart & Sörensen, 2003). However, the study did not control for any illness that may have a strong genetic/environmental factor to its development, which may impact on family carers who care for an individual with such an illness e.g. Alzheimer’s disease, diabetes, Huntington’s disease. In addition some of the risk factors (i.e. depression, older age, lower SES and low support levels) would be likely to give rise to poorer physical health in non-caregivers also. These studies of physical health in informal caregivers indicate that they are potentially at risk of poorer health compared to non-caregivers and that a multitude of factors could be associated with this, such as caring demands or depression. Another important factor in caregiver health appears to be the level of psychological distress.

1.5.3 Psychological / Emotional
Pinquart and Sörensen (2003) found that caregivers as a group reported higher levels of stress and depression compared to matched non-caregivers. In addition, they had lower levels of subjective well-being and self-efficacy (Pinquart & Sörensen, 2003). These effects were strongest for carers of older adults with dementia. Non-dementia carers differed from dementia carers as only dementia carers had higher ratings on depression and self-efficacy compared to non-caregivers. This may indicate that there may be something specific about dementia care-giving. However, a breakdown of the demographic data was not provided. As the majority of carers were spouses (58.5%), it may be that the majority of dementia carers were spouses and as such represented an older population when compared to the non-dementia carer group. Therefore the findings may have highlighted demographic differences between the
groups. Indeed in their analysis significant effects were found with older caregivers more likely to have higher levels of depression and lower levels of self-efficacy. Significant gender effects were found and whether the carer was a spouse or not also influenced the results. While the main finding that carers are more at risk of stress and depression is important, the additional findings which break down the caregiving group may need further interpreting due to other variables beyond carer status significantly impacting on the findings.

Hirst (2005) conducted a longitudinal prospective study into carer distress compared to non-carers. Distress was measured using the General Health Questionnaire-12 (Goldberg & Williams, 1991) to allow a more general measure of distress than specific measures focusing on diagnosable disorders such as depression (Hirst, 2005). A small increase in distress levels was found when an individual commenced their caring role, with a significant increase when twenty or more hours of care per week was provided. This study also showed that distress did not alleviate immediately once the caring episode had ended. Instead there was a steady decline, with distress levels not matching those of non-carers until five years post caring in ‘heavy’ carers (>20 hours per week) and three years post caring in those who cared for less than twenty hours per week (Hirst, 2005). Thus indicating that there may be long term distress associated with caring, even once the source of the stress has been removed. While there is likely to be a confounding issue of bereavement or care-recipient health decline, possibly shown in the study by an increase in distress at the transition out of caring point, it may still be reflective of other processes unique to the caring role (e.g. loss as a result of the caring role ending). Future studies should attempt to measure these processes in caregivers, particularly against a matched group of non-caregivers who have had a recent bereavement, to examine if the distress trajectory is similar when bereavement occurs. Studies examining carer distress in non-dementia populations have also found similar results with caregivers being at greater risk of emotional distress and lower well-being than non-caregivers (McKeown et al., 2003).
Pinquart and Sörensen’s (2007) meta-analysis found that depressive symptoms were more strongly related to poor caregiver health than factors such as informal/formal support, hours of care provision and number of care-giving tasks. This is an important finding as presently a lot of resources are centred on reducing the caring burden by increasing the level of formal care, through interventions such as respite. However, this study indicates that interventions targeting depression may be important; not only to improve depressive symptoms, but also to improve the risk to the caregiver’s health. As the study is not longitudinal and only includes current carers it is unclear that the depression and poor health association is a by-product of the caring role, or whether the study just supports existing knowledge such as those with poor health are more likely to be depressed. It does highlight the need for consideration of the carer’s own physical and mental health. However, the study only sampled informal carers of older adults, with 48% of the studies related to dementia care-giving. The studies examined in the meta-analysis are also observational so further research is required on the use of depression-focused interventions in caregivers compared to interventions aimed at reducing objective stressors such as reduced support, hours of care-giving. This would allow a more detailed examination of the association between depression and physical health in caregivers. As Pinquart and Sörensen (2007) acknowledge more information is required about the carers, such as pre-existing illnesses and whether carer health declines in line with their caring role.

Obtaining accurate information regarding the prevalence of psychological distress in informal caregivers is challenging due to a number of factors. Firstly distress is conceptualised differently between studies, for some it is depression or anxiety whereas others use the term with less specificity to disorders and others seem to use distress in relation to well-being measures. Studies often do not state whether carers are reaching the clinical cut-off point on psychological measures or are just reporting higher scores. Studies also tend to use the terms burden, distress and emotional distress interchangeably and there is often no theoretical distinction between these terms indicated in the study methodology. There is also often a lack of standardised
measures used to measure psychological symptoms and when used there is a lack of consistency across studies making the generalisability of results between studies difficult.

In summary, around 12% of the UK population currently undertakes a caring role with the number of informal carers likely to rise in future years (Pickard, 2008). Informal carers are at risk of poorer outcomes in a number of areas compared to non-carers. Due to the potential for negative outcomes, such as poorer physical and psychological health, there is a need to support carers in their caring role. This has benefits not only for the informal carer and the carer/care-recipient dyad but also financially for health and social care departments.

1.6 Models of Caring
A number of models have been developed to understand the caring process. Initially these were simple models with increased stressors leading to poorer outcomes. However these models have become more comprehensive, as the literature base has grown, to focus on the mediators between stressors and carer outcomes as research has indicated there only to be a weak relationship between caring stressors and outcomes (Zarit et al., 1980; Haley et al., 1987). Some of the leading models of caring will now be discussed.

1.6.1 Stress-Appraisal Models
Stress-process models of care-giving examine factors that influence how stressors are experienced by informal caregivers. They generally include four main factors, stressors; appraisal; outcomes and contextual information (Yates et al., 1999). Early models focused on appraisal, coping responses and social support as mediators of outcomes (Haley et al., 1987; see Figure 1.1) which was in line with widely accepted stress-coping models (e.g. Lazarus & Folkman, 1984).
Hayley et al. found support for their model with dementia carers. In line with previous research, they found no correlation between stressors and outcomes. Correlations were found between carers’ appraisal, particularly negative appraisal of their ability to cope and the carers’ behavioural difficulties. Correlations were also present between positive coping responses such as problem solving and information seeking and more adaptational outcomes, as well as correlations between higher social support and positive outcomes. Multiple regression analysis on their sample indicated that appraisal, coping responses and social support did significantly predict caregiver outcome, and therefore provides some support for their model. A strength of this model is that it proposes potential areas of intervention for carers beyond attempts to reduce the caregiver burden by reducing the objective burden (i.e. respite). Instead the model proposes that it is subjective burden (through appraisal), maladaptive coping responses and poor social support which may be important for carers. There are some problems with how the data was analysed as the regression analysis was run using a sample size of 52, which suggests the study is underpowered as analysis suggests with three variables a minimum sample size of 74 would be required to detect a medium effect (Green, 1991). They also combine a
number of their variables to create new predictor variables to use in the analysis; this potentially dilutes the model as it is unclear within each variable what might be accounting for the variance. For example, with social support it could be hypothesised that the quality of social relationships predicts more of the variance than the quantity, however as they have combined these measures together to create a new variable, information such as this is lost in the analysis. Even though there are a number of limitations with Hayley et al.’s model (1987) it still created a model to understand carer outcomes and to suggest ways of intervening positively for carers, which other models have developed on.

Later models expanded on this work and included contextual information such as previous experiences and potential processes that may precipitate or ameliorate the experience of distress in informal carers (Pearlin, 1990). These models allow the exploration of primary stressors associated with the caring role in addition to secondary demands from additional objective and subjective stressors. However, a limitation of these models is that they do not allow an individual’s appraisal processes to be explicitly explored (Yates et al., 1999). Instead they focus mainly on carers’ coping mechanisms and experiences, neglecting the relationship between the carer and the care-recipient (Yates et al., 1999).

Appraisal models have been developed to take account of these processes. Lazarus and Folkman’s (1984) stress-coping model is an early example of consideration of an individual’s appraisals of an event as threatening or benign. As discussed previously Hayley et al.’s study (1987) looked at appraisal of the care-recipients behaviour and the carer’s appraisal of how they are coping. However, these types of appraisal were not specifically mentioned in the model. Lawton et al. (1991) developed an appraisal model specifically for caregivers where subjective appraisal of the care-giving role was described as a mediator between the stressor and measures of wellbeing. The appraisal model adds to the stress process model by considering this relationship and including it in the model. The model though has received criticism due to not having
clear distinct components. For example, the appraisal construct overlaps with resources and coping strategies therefore perhaps making it a less useful process in the model as it has not been clearly defined (Braithwaite, 1996). In addition, the stress and appraisal aspects in the models are not entirely distinct and the appraisal components include aspects of stress (Yates et al., 1999). The criticisms of both models led to the development of a combined conceptual model, which will now be discussed.

1.6.2 Combined Conceptual Model
Yates et al. (1999) attempted to develop a new model of caring incorporating aspects of the stress and appraisal models (see Figure 1.2).

Their model includes the appraisal aspects of hours of care and overload. They theorise that these aspects are appraisals as it is the carer who evaluates the level of care and the level of overload, which is conceptualised as subjective burden (Yates et al., 1999). The primary stressors could be described as objective burdens. Support was found for the model as the primary stressors were found to be related to depression through the appraisal variables (Yates et al., 1999). The largest mediator of depression was mastery which was also linked to emotional support (Yates et al., 1999). No effect of formal service hours was found which is linked to later research on respite, which indicates that while carers find respite positive there is little long-term impact on carers’ level of burden, distress or well-being (McNally et al., 1999, Mason et al., 2007).

Yates et al.’s. (1999) model adds to the care-giving research by highlighting that appraisal processes are important factors for informal carer outcomes in conjunction with level of stressors. However it lacks a description of coping strategies. The model conceptualises that the mediators will influence carer’s appraisal of how burdened they are. It is likely within this appraisal of burden that the informal carer does analyse how they are coping but this does not allow an exploration of how different coping styles may influence perceived levels of burden and whether it is
manageable for the carer. Coping should perhaps be included as a mediator. Yates 
et al. (1999) also do not explain in detail why the mediators were chosen in the current model, although they draw on previous models such as Pearlin 
et al. (1990) and Lawton et al. (1991). However, a strength of the model is that it may allow different mediators to be explored within its framework, thus allowing interventions based on theory to be designed.
Figure 1.2 Yates et al. (1999) conceptual model
1.6.3 Conservation of Resources Model

Hobfoll’s conservation of resources model (1989) aims to conceptualise the stress process. While this theory has not been specifically developed to explain carer stress it is relevant as it takes an overview approach to stressful situations and attempts to explain why certain individuals will be under stress in certain conditions. The model is based on the theory that individuals build up resources that are meaningful to them and try to retain/conserve these resources (Hobfoll, 1989). Hobfoll suggested that there are four types of resources, object resources (e.g. own home, car, higher socio-economic status); conditions (e.g. marriage, seniority); personal characteristics (e.g. optimism, mastery) and energies (e.g. time, money, knowledge). Energies are also related to the ability to acquire additional resources i.e. an individual expends these to gain another resource. Hobfoll later developed a list of key resources, relevant to a Western culture (Hobfoll, 2001). According to this model stress arises at times when resources are threatened, lost or resources are not gained following a significant amount of investment (Hobfoll, 2001). This has similarities to Lazarus and Folkman’s model (1984) where it was suggested that an individual appraises an event as threatening or benign. If any of these situations arises it is hypothesised that an individual will attempt to offset their loss of resources through using their remaining resources. Therefore, individuals who are able to use their resources to adapt to a situation do not suffer with the same stress as those who are unable to adapt/conserve resources. The model aims to go beyond appraisal models by investigating why people make certain appraisals to certain events/stressors through theorising that if the individual values a certain resource(s) and these are threatened, lost or not gained then this will be appraised as a stressful event for that individual and likely experienced as stressful. Whereas if an individual does not value the resource that is threatened it will not be perceived to be as stressful as it is for the individual who values it.

In relation to the caring role Hobfoll’s model can apply in a number of areas. While caring for another, carers invest a number of their resources e.g. time, energy and may lose or have to reduce investment into the resources they value e.g. work, time with family, health. According to the model, carers who experience these reductions
in resources will try and restore them, for example thorough seeking help from others, which may help offset the resource loss experienced and could lead to resource gain. However, if it does not lead to a positive outcome there will likely be increased stress for the caregiver as they will have had to try and invest additional resources in order to offset the initial experience of resource loss, thereby experiencing further resource depletions. This may set them on a downward spiral of stress as they continue to try to unsuccessfully regain the lost resources. This negative impact of the caring role on the carer will likely effect carers who had more limited resources to start with. In addition, overtime the caring role may lead to carer burnout as the carer may continually invest resources into the role and fail to gain resources in turn.

This model may be useful in understanding the care-giving experience as it examines more widely factors which impact on carers, rather than it solely being about their appraisals/cognitions to the caring situation. This offers up opportunities to examine different types of interventions beyond more traditional cognitive models. For example carers could be assisted with regaining previously lost resources or to focus more widely on the situation so they can see areas where they can or have made gains rather than focusing on one resource. However, while this model has been applied to other stress situations, such as employment related burnout (Hobfoll, 2001), it has not yet been applied to carer related stress. Therefore this needs further development; however the premise of the theory does appear as if it may be applicable to carers.

1.6.4 Limitations of Current Models
All of the models discussed, excluding Lazarus & Folkman (1984) and Folkman (1997), use dementia or older adult caregivers as their sample to assess their models validity. This creates difficulty in the ability to generalise the model to other types of caring, such as caring for an adult child, peer relative or caring for someone without dementia or frailty due to old age. This is particularly true of models which add criteria such as cognitive impairments as a stressor which may only be applicable to
those with dementia or neurological conditions. Yet the authors do not describe their models as models of dementia care-giving rather they are relating them to carers more generally. If general care-giving models of carer outcomes are being developed it may be more useful to use more general labelling such as in Pearlin et al’s. model (1990) i.e. care-recipient behaviour/care-recipient needs, which could then be explored in more detail with different carer groups.

Another limitation is the lack of focus on positive outcomes. Yates et al’s. (1999) model also does not include a conceptualisation how these positive outcomes may influence the carers outcome. Folkman (1997) revised the original model of stress and coping (Lazarus & Folkman, 1984) to allow the inclusion of meaning based coping as a mediator of distress resulting in positive emotion. There is a need for consideration of the positive outcomes for carers as positive experiences are neglected in current models even though the research clearly indicates they exist. An exception to this is Hobfoll’s (1989) conservation of resources model which would hypothesise that gain, experienced through resource gain, could help ameliorate the potential negative effects of caring due it offsetting the experience of resource loss. Thereby helping to explain why some carers experience minimal or no negative effects from their caring role in comparison to others. These could perhaps be considered as possible mediators of distress, like in Folkman’s model where type of coping appears to mediate distress, allowing positive emotions to co-exist.

In summary, it appears that current models of care-giving do not fully explain the many aspects of the care-giving role and the factors that may mediate distress. A key factor that appears to be missing is a consideration of the positive aspects of the care-giving role, which has been frequently identified as being related to the opportunity to find meaning that can occur as part of the care-giving role. These positive experiences and the factors leading to their occurrence may be important in reducing the negative outcomes of the care-giving experience. These aspects will now be explored.
1.7 Positive Aspects of Care-giving

It is increasingly recognised that informal carers can derive many positive benefits from their role which may protect them from the potential negative effects of care-giving. It is important to examine such relationships as this may suggest factors that may be protective against psychological distress and negative outcomes. Research into positive aspects of care-giving has really only come into fruition in recent years. An early study by Folkman (1997) helped provide evidence of the positive aspects.

Folkman (1997) studied AIDS care-giving and alongside the expected high levels of negative psychological states a similar level of positive states was found. This was an interesting finding as it indicated that even in a highly stressful caring role (where a partner was dying) positive and negative affect could co-exist. This study highlighted an omission in the earlier stress coping model (Folkman & Lazarus, 1984) which hypothesised that positive affect only occurred in stressful situations once the stressor had been resolved. The finding that well-being can be high even in adverse situations is important as by using the earlier model as a guide then care-giving stress would only be expected to resolve once the caring role had ended if the caring role was the stressor (Folkman & Lazarus, 1984). Instead Folkman (1997) identified that an individual’s coping style influenced their ability to experience positive emotional states. Specifically, if positive re-appraisal, goal-directed problem focused coping, spiritual beliefs and practice and the infusing of ordinary events with positive meaning styles of coping were used then the carers still reported positive emotional states even when the stressor was present. The underlying theme of these styles is finding meaning (Folkman, 1997). Folkman’s revised model hypotheses that meaning based coping helps alleviate distress in situations where a stressor cannot be resolved or is resolved unfavourably (Folkman, 1997). Therefore meaning based coping may help moderate the negative affect associated with the stressor, resulting in a positive emotion, even though the negative emotion may still be present. Thus, if a stressor is present but with accompanying positive emotions,
the carer may report being burdened yet have overall positive well-being due to their meaningful based coping.

While Folkman’s 1997 study did not directly measure well-being against stress, other studies have done this. Chappell & Reid (2002) conducted a study examining burden and well-being in carers. The main finding of their study was that while burden and well-being were found to be related they were still separate constructs due to factors, such as social support, being related to burden but not well-being, therefore indicating that burden and well-being were not measuring the same thing. This suggests that well-being can be enhanced even with burden (stressor) being present (Chappell & Reid, 2002), which is similar to the Folkman’s findings.

In summary, existing models of care-giving fail to take into account positive aspects that occur in the caregiver as a result of the caring role and how these might in turn positively influence their experience. It is hypothesised that these positive aspects may account for why some caregivers report no negative effects as a result of their caring role. Perhaps the positive aspects provide a buffer against the burden effects resulting in positive well-being even in adverse conditions where distress is present is likely to be one way in which this occurs. The current study proposes that mindfulness and aspects of ACT (psychological flexibility and valued living) may be a way of buffering against the stressors and allowing positive emotions and well-being to exist even when carers are burdened.

1.8 Well-Being and Distress
The current study proposes that it is relevant to measure both well-being and distress and through doing so postulates that they are separate constructs. However, there is debate over whether this is the case. This evidence will now be briefly discussed as it provides additional background for the current study as to why distress and well-being are considered separately.
Within psychology there is ongoing debate regarding psychological distress and well-being, particularly if one is measured, whether it is necessary to measure the other. This is because it has been thought they are opposite ends of the same construct. In line with this viewpoint if someone has high distress they are therefore unlikely to be high in well-being and vice versa. However, this is a simplistic approach and the current study does not conceptualise well-being solely as an individual having positive affect, rather it is more in line with Huppert’s conceptualisation of well-being. Where well-being can be feeling good or experiencing positive emotions, but it is also about effective functioning. Therefore even when someone is not feeling good or happy they may still get some sense of mastery over the activities that they perform (Huppert, 2009). Well-being is perhaps also more wide-ranging than just a discrete experience of positive or negative affect. While someone may have experienced some negative affect/experiences over a discrete time frame they may still have good well-being. Huppert (2009) proposes that well-being can be affected if the distress/negative emotions a person experiences are long-lasting or impacts on functioning. The impact on functioning is important as the variables in the current study, valued living, psychological inflexibility and mindfulness focus more on functioning and living with negative experiences/emotions rather than avoiding them. Therefore, the current study proposes that even with negative experiences (distress/burden) well-being could be maintained.

There has been evidence for positive and negative affect being opposite ends of the same construct and therefore negatively correlated. Suggesting the experience of both simultaneously is not possible (Russell, 1980). This circumplex model of emotion was later revised and the stance changed to polar opposite emotions being mutually exclusive (Russell & Carroll, 1999). So, the experience of one (e.g. distress) cannot occur at the same time as another (e.g. happiness). Thereby negating the need for there to be a negative correlation between the two.
However, there have been criticisms that initial findings that positive and negative affect being the same construct have not been replicated (Diener and Iran-Nejjad, 1986; Larsen et al., 2001). Evidence from their studies suggests that positive and negative emotions can exist together, especially in emotionally complex situations (Larsen et al., 2001). It is important to bear in mind that well-being is not just about positive affect/feeling good, but also about effective functioning; therefore it is not just a polar opposite of distress/negative affect. Therefore, it may be important to consider well-being in addition to distress.

Caring could be conceptualised as an emotionally complex situation. Generally the carer is taking on extra demands with the caring role, often they may wish to care for the person or feel pressure to do so (an expectation to care). There is also the evidence that there can be gain within the caring role, which could be hypothesised as a positive effect of the role. That while they may feel stressed and/or distressed due to their caring role they may have positive emotions related to it. Evidence for this was found as even in distressing situations (i.e. care-recipient death) carers still reported good well-being (Folkman, 1997).

As there is no clear evidence that distress and well-being are the same construct it is perhaps relevant to include both. In addition there are reasons as to why measuring both concepts may be beneficial. As noted in section 1.7.3 criticisms of caring models have highlighted the lack of consideration for the positives gained from the care-giving role. Gain in this sense is not viewed dichotomously whereby you either have gain and good well-being, or you have distress and poor well-being. Rather that the gain can come, even in the presence of the distress. That while there are known negatives associated with care-giving these can, for some, co-exist with positive features of care-giving. Therefore, the current study hypothesises that those high in distress may still have good well-being and that this may be moderated by mindfulness, psychological inflexibility and/or valued living.
Secondly, within ACT (where the concepts of psychological flexibility and valued living originate) and mindfulness literature, well-being and distress are treated as separate. Conceptually both postulate that you do not have to live in the absence of distress in order to have good well-being and to live a fulfilled life. Rather that you can live with the distress (physical or psychological) and still maintain a purposeful life with good well-being. Therapeutically both ACT and mindfulness do not aim to reduce the cause of distress and as discussed previously the cause of distress cannot always be ameliorated. Rather they help the individual to work with their distress and to strive to achieve in spite of it. An outcome of this may be that the distress reduces as the individual widens their focus and engages in aspects of their life they were previously closed off to. However, this is not the intrinsic aim of mindfulness or ACT. Therefore, mindfulness and ACT do not solely focus on distress and well-being as unable to co-exist and as they are the core concepts being investigated in this study it would be short-sighted for the current study to just focus on one of the two.

Another argument for the inclusion of distress and well-being is that only studying the absence or presence of distress leaves gaps in understanding. Even within definitions of health well-being is explicitly stated as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (World Health Organisation, 1948). With the evidence suggesting there is not a complete overlap between distress and well-being and social definitions of health/ill-health not merely being about the absence of ill-health, disease or disorder then it may be short-sighted for research only to focus on the one aspect. There is further support for this viewpoint from Keyes’s population study (USA) on mental health and mental illness (2005).

Keyes proposed that the absence of disorder does not equal a healthy and productive life. The results suggest that well-being should be used as an outcome measure as it
is not enough to only measure distress, or disorder. Individuals’ may be free from disorder but still may not be ‘flourishing’ as represented by their poor well-being. Therefore the study of well-being may be important as just examining absence of disorder may not be representative of peoples’ experiences.

Given the current economic climate it may seem less important to study those with poor well-being compared to those who have a diagnosable condition which is having a large impact on their life and are seen as those in need of effective treatments. However, there is some evidence emerging that those with poor well-being may be at risk of future mental health problems. Wood and Josephs’ (2010) study found that poor well-being predicted future depression, even when past depressive episodes had been controlled for. Suggesting there may be benefit in researching well-being and examining potential interventions, even when disorder is not present. However, in this study it was unclear if past depressive episodes were included beyond the period when the study commenced. Participants were part of a longitudinal cohort study which began in 1957. Available participants were entered into the study aged 51-56 years and completed the questionnaire pack, which included a depression measure. The same pack was completed when they were aged 63-67 years. The study did control for the past depressive episodes at time one (51-56 years old) and found the result that poor well-being predicted depression at time two. However, there does not appear to be a measurement of depression prior to time one. Therefore it is unknown whether participants had earlier episodes of depression, so the results are less clear cut as it could be that past depressive episodes lead to poorer well-being. Even with some criticism regarding sampling it is an area that requires further examination, particularly as health care is moving towards a preventative rather than reactive model.

The current study measures both well-being and levels of distress. As discussed, research is not conclusive about well-being and distress being opposite ends of the same construct. Carers’ research needs to focus not only on distress as it has been
noted that there are many positives in undertaken a caring role. Therefore the current study does not solely focus on distress. The consideration of well-being may be particularly important when the constructs of mindfulness, psychological flexibility and valued living are examined. These constructs do not focus on the reduction of distress; rather they are more concerned with living with distress. A by-product of this may be the reduction in distress if the individual opens up to alternative experiences and is not solely focused on distress. However it is often noted that this is not the primary aim, therefore if the current study were to focus only on distress it may miss important parts of the very processes it aims to measure.

1.9 Mindfulness, ACT and Carers
The current study proposes that mindfulness and ACT may be potentially beneficial for carers. When discussing ACT, it is not the therapeutic approach that is being considered rather some of the processes that make up the ACT approach. Namely psychological flexibility (acceptance), valued living and mindfulness. It may be that ACT as a therapeutic approach could assist carers but at the moment the study is concerned with examining whether some of the processes may be helpful to carers. Likewise with mindfulness, the study is not aiming to increase carers’ mindfulness, rather examine whether the presence or absence of mindfulness, at a baseline level, may influence carers experience. This brief section aims to explain why mindfulness and components of ACT may be relevant to carers. For a full discussion of mindfulness and ACT see chapters 1.12 and 1.13.

As discussed in section 1.7.3 a criticism of caring models have been the focus on the negative aspects of the care-giving role with little consideration to the gain that can be achieved from caring and how this may impact on the carer. In Yates et al.’s. model (see figure 1.2), they describe that formal services, quality of relationship, emotional support and mastery mediate whether a carer is overloaded by the stressors related to their caring role. The current study proposes that mindfulness, psychological inflexibility and valued living may moderate the relationship that has
been found in the caring literature between distress, burden and well-being. That these factors could impact on an individual’s appraisal of their situation.

It is important to consider how individual appraisal occurs and how differences in this may impact on distress or well-being. This partly may be achieved through examining the coping responses a person uses in a stressful situation. The current study examines this through proposing that mindfulness, psychological flexibility and valued living may impact positively on how an individual appraises their caring role. Mindfulness, psychological flexibility and valued living are not being conceptualised as coping responses in this study. This is because these concepts are more wide-ranging that just how an individual copes with a stressful situation. It may be that individuals who are higher in mindfulness, psychological flexibility and valued living are more likely to use a particular coping style or use these approaches to help deal with a stressful situation. However, mindfulness, psychological flexibility and valued living are not just used in stressful situations but in everyday life, therefore they are not a coping response as they are not only present in the event of a difficult situation or emotion. In the caring role they may impact on how an individual appraises their role, incorporates in into their life and deals with stresses that may arise as a result. It is important to consider the appraisal process in carers as often this may be the only part that is changeable while they are caring. In addition research has indicated that it may not be the practical aspects of the caring role that gives rise to stressors (Zarit et al., 1980; Haley et al., 1987) and these stressors also may not be changeable.

Evidence for this can also be found within the carer literature. Evidence for the use of respite in carers is mixed. A review by McNally et al. (1999) suggested limited evidence of long term benefits in terms of carer well-being or level of stress/burden following respite. From the 29 studies reviewed the results were variable and as such no firm conclusion could be drawn. It appears that respite can have a positive effect on wellbeing during the respite period; however this effect diminishes during the
follow-up period (McNally et al., 1999). Only one study found a positive long-term effect for carers (Hinchcliffe et al., 1995) where mental health outcomes were maintained at 16 weeks post respite. The respite used in this study was supplemented by an intervention focused on developing activities outside the home which carers received during the respite period (Hinchcliffe et al., 1995). Given the lack of positive outcomes in other respite-only interventions it is possible that the active component was not the respite but the added carer-focused intervention as this was not controlled for.

A more recent review by Mason et al. (2007) found similar outcomes, with respite interventions demonstrating only small effect sizes on caregiver burden and mental/physical health. It was unclear if there were any long-term effects of the intervention as follow-up data was not presented. This may have been due to a lack of post-intervention follow-up in the original studies. Only eight studies measuring carer burden met the inclusion criteria of the review and only two of these found a significant effect on caregiver burden as a result of respite. Mason and colleagues’ study (2007) was also only concerned with respite for the frail elderly and therefore their results may not be generalisable to other carer populations. In line with other studies (McNally et al., 1999; Victor, 2009) they found that generally carers were very satisfied with respite, despite modest or statistically insignificant measurable benefits in terms of reduced burden and carer health.

Carer distress therefore may be about more than just the demands placed on the carer as part of their caring role. Reviews have been completed on carer interventions but no clear gold-standard intervention has emerged. This may suggest that some of the factors that contribute to the distress that can occur as a result of caring have not yet been understood; therefore an appropriate intervention has not been developed. This has been one of the key criticisms to carer interventions (Parker et al., 2010). It may be that the caring role is one which is complex with many factors influencing it (e.g. the carer-recipient’s diagnosis and prognosis, the physical/mental consequences of
their diagnosis, carer demands out with the carer role, carers own health, level of
support available, relationship with carer-recipient, appraisal factors, coping style
e tc.) and there may be a contributory relationship between many factors with
individual differences. However, just because something is complex does not mean
it should not be studied and that different theories cannot be applied as a way of
trying to understand. A key feature of mindfulness and ACT is that they have not
been developed for a specific disorder, rather more generally to help individuals
manage stress/distress more effectively and to increase a sense of well-being.
Therefore they may have benefits for carers when there may not always be a
diagnosable mental health condition present to treat but the carer still feels stressed
and has poor well-being. In addition the cause of the distress, the caring role, may
not always be changeable.

The next section discusses how mindfulness, psychological flexibility and valued
living may add to existing models of care-giving in explaining potential moderators
between burden, well-being and distress. The factors will be discussed with regard
to the processes by which they may allow positive emotions and outcomes to arise
during the care-giving process. In future this may allow targeted interventions to be
developed with the aim of reducing negative outcomes in care-giving.

1.10 Mindfulness

1.10.1 Definition
Mindfulness is thought to be a capacity which everyone can exercise, though the
extent to which people are mindful varies and can be increased through training, such
as individual mindfulness practices or group mindfulness programmes such as
mindfulness based stress reduction (Brown & Ryan, 2003). The origins of
mindfulness are in Buddhism, though it is now widely practiced without any
religious connotations (Baer, 2003). There are many variations in how mindfulness
has been conceptualised with different authors highlighting the importance of
different facets of the concept. A definition of mindfulness which is frequently used within the literature is by Kabat-Zinn (2003).

[Mindfulness is] the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of the experience moment by moment. (p.145).

Bishop et al. (2004) conceptualises mindfulness as having two components. The first component is considered to be the self-regulation of attention onto the immediate experience, which links in to paying attention on purpose to the present moment. The second component is theorised to be open, curious orientation to ones’ experience with acceptance of the experience as it is, therefore experiencing the moment without judgement (Bishop et al., 2004). Therefore by consciously focusing attention onto the current moment and being fully open to what arises without attempting to judge or change the experience then a state of mindfulness has been reached. How mindfulness may help with distress and the evidence base for this shall now be discussed.

1.10.2 Mindfulness and Psychology
As mindfulness originates within Buddhist practices it is not a new concept, however it gained popularity following Kabat-Zinn’s work on how people adapt to chronic illness and pain. His eight week Mindfulness Based Stress Reduction (MBSR) programme enables people to recognise how their relationship to their illness or pain, rather than the condition per se, influences the degree of suffering they experience. When this relationship is characterised by aversion, avoidance or clinging to the experience then the suffering can be significantly worse than when the relationship is characterised by compassionate, mindful acceptance. This is that mindfulness allows the individual to accept that their experiences are difficult and that it is acceptable to experience this.
Using Bishop et al.’s. (2004) conceptualisation of mindfulness, it is hypothesised that mindfulness impacts positively on how individuals relate to their stressful experiences. Through regulating their attention deliberately, they can be aware of when difficult thoughts or emotions arise and avoid rumination on these. It differs from thought suppression (avoidance) which is important as evidence indicates that thought suppression is a futile exercise (Weger et al., 1987). Rather than suppress the thought/emotion, individuals, through mindfulness practices, learn to purposefully pay attention to their internal and external experiences and acknowledge the thoughts/emotions that arise and to be accepting of them. Acceptance is important as it avoids the suppression of the thought/emotion as well as attempts to change or compare it to other things. This is important as trying to change the experience keeps it active and allows rumination to occur. Thoughts are also accepted as they simply are, as thoughts, not as truths about events/experiences. These processes are considered to have a positive impact on individuals’ experience of stress and difficulty in two ways; through the avoidance of thought suppression and by the accepting stance, allowing thoughts and emotions to be seen from a more detached and balanced perspective.

1.10.3 Mindfulness Evidence Base
The key articles reviewed are summarised in Table 1.1. Meta-analyses and systematic reviews were chosen to review the evidence base to provide a brief overview.

The use of mindfulness as an intervention within psychology has received a lot of interest in clinical practice and as such research has been forthcoming to assess its efficacy. Mindfulness Based Cognitive Therapy (MBCT) has been included as an intervention in the NICE depression guidelines (2009). This inclusion was partly due to Teasdale et al.’s. (2000) randomised controlled trial of MBCT which indicated that it significantly reduced the risk of recurrence of a depressive episode when an
individual has had three or more previous depressive episodes (Teasdale et al., 2000). MBCT is a modified form of MBSR which was developed specifically for depression relapse prevention. It differs from MBSR as it introduces cognitive behavioural components and emphasises the importance of the relationship between thoughts, feelings and behaviours (Segal et al., 2002).

The evidence base for MBSR is encouraging and studies have shown it to be beneficial for the treatment for a number of conditions such as anxiety and depression (Grossman et al., 2004). This is relevant to carers due to their increased risk of developing psychological conditions (see section 1.4.3). While results of Grossman et al.’s meta-analysis (2004) are encouraging, there are limitations with the studies included. The inclusion criteria required mindfulness interventions to last between 6-12 weeks, suggesting that the standardised 8 week MBSR programme was not used in some studies. In addition Grossman et al. (2004) note that none of the studies used pre-post intervention measures of mindfulness. So, while it appears that mindfulness interventions may positively impact on the outcomes measured, there is no evidence of participants’ level of mindfulness changing as a result of the intervention. Therefore, it cannot be concluded that mindfulness is the component which impacted on the outcomes. This is a criticism of a lot of the mindfulness research, as there is often a lack of evidence that participants’ levels of mindfulness are also changing as a result of the intervention due to studies not measuring the construct.

Hoffman et al.’s (2010) meta-analysis of mindfulness interventions found a moderate effect size in reducing anxiety and depression. While their meta-analysis found the largest effect sizes when participants had diagnosable anxiety and depressive disorders, moderate effect sizes were found when individuals had lower levels of anxiety and depression. This may indicate that mindfulness has a positive impact on general everyday stress levels in addition to diagnosable mental health problems.
This is in line with existing research that indicates MBSR is potentially useful in managing stress for people who do not have a diagnosable mental health condition. A Dutch study randomised a group of participants (N=60) self-reporting to be distressed, though without psychological disorder, to a mindfulness intervention group or wait list control group (Nyklíček & Kuijpers, 2008). The results of the study indicate that MBSR decreased distress and increased quality of life. Interestingly they found that general mindfulness, as measured by the Mindful Attention Awareness Scale (Kirk & Brown, 2003) mediated the change in perceived stress, quality of life and vital exhaustion (Nyklíček & Kuijpers, 2008). The potential efficacy of the use of mindfulness in populations without a diagnosed mental or physical health condition is particularly relevant as while it is known that carers are at increased risk of psychopathology and poor health (see section 1.4), clearly not all carers have a mental health diagnosis. A large number though report high levels of stress and it may be that delivering mindfulness interventions to carers may help them manage stress more effectively, impacting on their well-being and ability to continue to care.
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<th>Authors</th>
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<th>Weaknesses</th>
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<tr>
<td>Grossman et al. (2004).</td>
<td>N=20 studies</td>
<td>Meta-analysis</td>
<td>Mindfulness main effect size of 0.5 for mental health and 0.43 for physical health.</td>
<td>Examines different outcomes. Stringent inclusion/exclusion criteria.</td>
<td>No comparison to existing interventions, though this was not the aim of the study. Subject population showed heterogeneity indicating significant differences in combining of the different populations. This may have impacted on results.</td>
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<tr>
<td>Hofmann et al. (2010).</td>
<td>N=39 studies</td>
<td>Meta-analysis</td>
<td>Mindfulness moderately effective for improving anxiety and mood symptoms. When sample reduced to examine anxiety and mood disorders, effect sizes increased to give a large effect.</td>
<td>Separation of disorders vs symptoms. Examination of MBCT and MBSR separately. Examining follow-up effects.</td>
<td>Unclear description of range of years in search strategy (first available year – April 1st 2009). Few databases searched (3). Mean Jadad score for included studies = 1.</td>
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<tr>
<td>Nyklíček &amp; Kuijpers (2008).</td>
<td>N=60</td>
<td>Randomised trial, MBSR group v wait list control</td>
<td>MBSR group showed significant reduction in perceived stress and vital exhaustion alongside increased positive affect, quality of life and mindfulness, but no significant differences from the control group.</td>
<td>Measured independent mindfulness practice. Used MBSR protocol.</td>
<td>Poor highlighting that the intervention group did not significantly improve compared to control. No long-term follow-up.</td>
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<td>Effects of mindfulness-based stress reduction intervention on psychological well-being and quality of life: is increased mindfulness indeed the mechanism?</td>
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<th>Teasdale et al. (2000).</th>
<th>N=145 participants with a history of recurrent major depression</th>
<th>RCT with 2 groups; treatment &amp; treatment as usual (TAU)</th>
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<th>No measure of mindfulness therefore cannot be certain it is the mechanism of change above other aspects of the programme. Results specific to recurrent depression. No control of whether participants soughted other therapeutic help during the study.</th>
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However there are criticisms of the research base, mainly a lack of active control groups, as opposed to waitlist or treatment as usual control groups used in the studies. The use of control groups is important to assess the impact mindfulness has when compared to existing interventions and to control for group effects. This is to ensure there is something specific about the mindfulness group which cannot be explained by group attendance, additional attention or peer support. There are also no longitudinal studies which examine the long term effects of mindfulness interventions and whether therapeutic gains are maintained. Unfortunately a lot of these criticisms remain, even with newer research being carried out. A recent systematic review of mindfulness randomised controlled studies still highlighted these flaws in the research base (Fjorback et al., 2011). The review does support MBSR as impacting positively on mental health, but further research is required to fully demonstrate this. Fjorback et al.'s. study (2011) separated out clinical population studies from non-clinical populations, finding MBSR to improve mental health in both populations. This is relevant to the current study, given, as mentioned above, carers as a group consist of both those with a clinical diagnosis and those without. An earlier study (Chiesa & Serretti, 2009) examined the use of MBSR for stress management in individuals who did not have a psychological or physical disorder. They completed a meta-analysis on ten studies which met their inclusion criteria. The results indicated that in randomised control trials (RCTs), where waitlist controls were used; those in the MBSR group had a significant reduction in stress. In the only study where MBSR was compared to active treatment (relaxation training) no differences were found, suggesting MBSR had similar outcomes to relaxation training. However the meta-analysis did not distinguish between length of the MBSR treatment and as a result short interventions were included. In the MBSR v relaxation training intervention the MBSR training lasted four weeks (Jain, 2007). This is half the usual time of the standard eight week protocol, which could impact on how well participants were able to learn mindfulness techniques.

In future there is a need for RCTs with different treatment arms such as a wait list, support group, education condition and an active treatment comparison group e.g.
CBT, with enough participants so results can be interpreted meaningfully. It is perhaps also important that initial studies do not try to modify the original MBSR or MBCT intervention for which there is an existing evidence base. If they do make modifications, they should be specific about these to allow replication. This is because it could impact the generalisability of results and potentially affect the treatment provided, thereby possibly impacting on the results. Baseline measures of distress need to include information about whether participants met clinical cut-off levels or were sub-threshold on measures of distress as existing evidence indicates higher efficacy for mindfulness interventions when participants are at a clinical level of distress (Hofmann et al., 2010). In addition studies need to examine pre-post measures of mindfulness to establish that this is a factor in the changes reported, particularly as many current studies lack this measurement, including key studies such as Teasdale et al. (2000).

1.10.4 Mindfulness and Carers
Mindfulness could be potentially relevant for informal carers to help them cope with what is recognised as a potentially stressful situation. Particularly as the source of the stress, the demands of the caring role, often cannot be fundamentally changed. In addition research suggests that it is often not the objective stressors of the role which leads to the distress, thereby suggesting it is more to do with subjective stress (e.g. Zarit et al., 1980). Individuals may need to find different ways of coping and managing the aspects of the role they find challenging. Mindfulness is an intervention which could be useful in such situations and has already been widely used in populations where active change of situations may not be possible, e.g. cancer patients, chronic pain and heart disease (Grossman et al., 2004). The use of mindfulness for carers could be a way of helping them deal more effectively with the stressful situations they find themselves in. This may be particularly important when these thoughts are anxious or depressive in nature. It could be hypothesised, therefore, that mindfulness could be a protective factor for some carers, with those with greater mindfulness being at lower risk of developing psychological distress. Evidence for the use of mindfulness in a carer population will be discussed in section 1.12.
1.11 Psychological Flexibility and Valued Living

Psychological flexibility and valued living are components of Acceptance and Commitment Therapy (ACT). ACT is based on Relational Frame Theory and takes the perspective that language is at the core of human suffering. This is that the labelling of experiences and events are linked to past events which can cause distress to be increased and maintained over time. ACT is part of the third wave of psychotherapies. It uses commitment, behaviour change, mindfulness and acceptance processes across six domains to produce greater psychological flexibility. ACT aims to enable people to make an active choice rather than just continuing down familiar but unhelpful paths. ACT is concerned with focusing on the here and now and experiencing it directly with a non-judging stance and using mindfulness to help achieve this.

An aim of ACT is to increase the extent to which a person is living in accordance with their values. Values in ACT are described as ‘chosen qualities of purposive action’ (Hayes & Strosahl, 2004, p10). Values are overarching and long-term. They differ from goals as the value itself is not achievable but the goals leading to and in accordance with the value are achievable. Values are the behavioural aspect of ACT. They are often described as the compass, which show the person the general direction which they are heading in with goals being defined along the way. It is values along with committed action towards values, which deliver the behavioural change. Committed action is the process of defining and completing goals in order to live in line with the identified values (Hayes et al., 2003). ACT uses processes such as acceptance and mindfulness to allow individuals to identify their core values, and to live in line with these values, acknowledging that there will be difficulties in doing so and using acceptance, mindfulness and psychological flexibility to help manage the difficult events, in the service of persisting with values based action.
1.11.1 ACT Definitions
Psychological flexibility has been described as being connected to the present moment more fully, with awareness so an individual can make a conscious decision to either change their behaviour or to continue in order to progress towards their values (Hayes et al. 2003). It is the overarching goal of ACT and is influenced by the six processes of acceptance, defusion, self as context, contact with present moment, values and committed action.

Acceptance, contact with the present moment and self as context are also parts of mindfulness (Hayes & Strosahl, 2003). Acceptance in ACT is about experiencing situations as they are without trying to change them and relates to thoughts, emotions and bodily experiences. Self as context is about letting go of fixed ideas about personal identity or an attachment to a particular image of self thereby allowing the self to emerge through immediate experience, as the perspective from which events are experienced. Cognitive defusion is the process by which separation or detachment from thoughts can occur, recognising them as simple mental events rather than as actual truths, and reduces their behaviour regulating qualities. This helps an individual to become less caught up in thoughts thereby reducing their capacity to create suffering and to become more engaged in the direct experience of life as it unfolds.

Values and committed action are the behavioural aspects of ACT. Values are the areas of life that an individual holds important and thereby indicate how they want to live. For example if someone held having supportive relationships as one of their core values, this value is not achieved just because someone is part of a family. Rather it requires behaviours which are in accordance with these values such as building relationships with others, sharing experiences with others, supporting others and allowing others to emotionally support them. These values can then be further operationalised through concrete everyday actions such as meeting a friend, which allows the behaviours consistent with supportive relationships to continue to be developed. Having an awareness of the valued direction can provide the
determination and courage necessary to face unwanted or difficult emotions that may arise on the way. Take as an example a person who values supportive relationships but is socially anxious. To cope with the anxious feelings they may attempt to avoid social situations. Unfortunately this avoidance would impact negatively on their value and also likely on their psychological well-being. In order to overcome this they can use the processes of acceptance and mindfulness to give them greater flexibility when in these difficult social situations, so they can choose to enter these situations even in the presence of anxiety. Therefore the negative feelings/thoughts associated with the situation continue to exist, however the individual feels able to tolerate and manage these feelings in order to continue to achieve the aspects of life they hold important.

1.11.2 ACT, Valued Living and Well-being
While values are individual there are general domains of values that are frequently identified. These domains are; family; intimate relationships; parenting; friendship; work; education; recreation; spirituality; citizenship and physical self-care (Hayes et al., 2003). An individual’s values often arise through exploration of what is painful. Experiences which are painful are often those which impact on our value system (Hayes, 2007). For example someone who is upset about a relationship ending, likely values relationships, if they did not value this then they would not be upset about the breakdown. Therefore instead of avoiding the painful emotions and thereby their values, the individual is encouraged to turn towards the pain (Hayes, 2007). This is often achieved through mindfulness to help clarify values to help the individual experience what is occurring within them at any given moment (Yadavaia & Hayes, 2009).

The importance of these value domains will vary in individuals and also will likely change depending on their stage of life (Wilson & Murrell, 2003). Values are used within the ACT framework to guide an individual’s progress through the therapy process. Obstacles to achieving goals congruent with their values are explored and the ACT core processes are used when necessary to increase psychological flexibility.
(Wilson & Murrell, 2003). The aim is not to remove the distress but to allow the person to tolerate the distress as it is in service of their value.

An individual not living in accordance with their values will avoid the situation, which in the short-term reduces psychological distress, however in the long-term psychological distress is likely to continue or increase. This is partly because avoidance is an effortful process; more energy, time and thought is spent on the actual problem situation and the distress it causes. In addition, a sense of mastery cannot be developed if individuals are not able to achieve what they want or live the life they wish.

1.11.3 Psychological Flexibility and Valued Living in Carers

These components of ACT are hypothesised to be potentially relevant to carers. Regarding psychological flexibility it is proposed that carers who have higher levels of psychological inflexibility will have lower levels of well-being and higher levels of distress. This is hypothesised because they will be less able to open up to other areas in their life in the presence of distress. Therefore, they may focus more on the stresses of the caring role and experience poorer well-being as a result. Valued living is considered important in two ways. Firstly, those carers who are able to live life in line with their values are likely to be more able to incorporate their caring role into one of their value systems and view their role as positive, potentially impacting on their well-being. Secondly, those with higher valued living may show that they are still able to be open to other experiences beyond the caring role, which may be enhancing their well-being. So, the caring role is not the only thing of importance in their life.

1.11.4 ACT Evidence Base

There is an emerging evidence base that indicates ACT and valued living can be associated with positive well-being. Meta-analyses reviewing the evidence base on
ACT were chosen to provide a brief overview of the current evidence base. An outline of the key papers reviewed are summarised in table 1.2.

Like mindfulness, research in ACT is in its infancy, particularly as ACT has only been established in mainstream psychology within the last twenty years. Initially proponents of ACT assessed the underlying process of ACT to determine if they were impacting positively on the psychological outcomes being investigated. The results of this, assessed in a meta-analysis, were promising with effect sizes when compared to existing treatments of \( d=0.66 \) (Hayes et al., 2006). However, little detail was given regarding the ACT and comparison treatments and only four out of the 12 direct treatment conditions contained a standardised psychological treatment. A high number of the interventions were delivered by proponents of ACT, which was noted earlier as a weakness to ACT studies (Hayes et al., 2004). In addition, the way that research was being conducted came under criticism (Öst, 2008, 2009). This criticism is that third wave RCTs, which includes ACT, have weaker methodologies than CBT research protocols and concluded that currently ACT is not an empirically supported treatment due to the methodological weaknesses. However, Öst’s study (2008) has come under criticism itself due to his conclusions and how they were derived. Gaudiano (2009a) argues that the matching and comparison of ACT to CBT studies was inappropriate as they were not matched by content of research, only by year and publication. Therefore, the methodologies of the studies would be different, particularly as a number of the ACT studies were examining more complex problem areas. In addition as a premise of ACT is that it can treat a wide-range of problems, not all the studies involved used DSM-IV diagnosis. Due to CBT being an established therapy, research into CBT has been developed over a number of years and can command significant funding grants, resulting in more refined and robust methodologies. Whereas ACT research is at an earlier stage of development, with less funding, and similarly to early stage CBT research weaker studies will be replicated and more rigorous methodologies will be applied in the future as the evidence base develops (Gaudiano, 2009b). Öst (2009) refuted this claim by suggesting that funding is not an issue as the areas that ACT research needs to
improve on do not require high costs. Arguing that ACT research should start at the same level and quality as CBT research. However this neglects the process by which new treatments develop their evidence base and the costs involved in running high quality methodological robust research protocols. The crux of Öst’s argument is that ACT does not meet the criteria of an empirically supported treatment (EST), however it likely that the studies used for comparison were not run to form evidence that ACT is an EST but to develop understanding into ACT and to begin to form, over time and a number of studies the evidence base. This is particularly true as a number of ACT studies were regarding examining the processes underlying ACT rather than its use as treatment per se.

Öst’s study (2008) highlights some of the methodological weaknesses within the ACT evidence base, which is something proponents of ACT recognise and are attempting to resolve with future studies. However, there is debate over the processes by which Öst used to arrive at his conclusions and whether the standards used to evaluate the research (comparisons of ACT v CBT, methodological rating scale used) where appropriate for the conclusions which were made. Yet, even with this criticism independent meta-analyses did indicate ACT to be a potentially efficacious approach with moderate effect sizes (Öst, 2008; Powers et al., 2009). It should be noted that the American Psychological Association has included ACT as an empirically supported treatment for depression and pain. While comparing ACT to CBT treatment in research should be encouraged to assess efficacy, perhaps less can be gained on a clinical level from comparing how ACT trials are run in comparison to CBT trials.

One of Gaudiano’s (2009a) arguments against comparing ACT against CBT based on year and publication was that a number of ACT studies focused on components of ACT or mechanisms of change rather than outcome based studies. This focus can be seen in Levin et al.’s. meta-analysis of laboratory studies (2012). These studies aim to examine the theory behind the ACT model rather than outcome. So, rather whether the separate components of psychological flexibility impact on psychological functioning, instead of a more global view of whether ACT treatment protocols improve psychological functioning through comparing pre-post measures or control
groups. These studies are a way of assessing the theory behind the ACT model. Levin et al’s. findings indicated that components of the psychological flexibility model did impact positively on psychological outcomes, thereby providing support for the ACT model. In addition differences between psychological flexibility components and conditions linked to fusion and attempts to control thoughts were found, with the ACT components tending to impact outcomes favourably. Interestingly, there were no significant differences found between different populations used in the study (convenience sample v at-risk/distressed). This suggests that ACT processes apply in the same way to those who are distressed as to those who are not. However, it is interesting that no differences were found, as part of the theory behind ACT is that those who are distressed are likely to have less psychological flexibility, which in part leads to their continued experience of distress. Therefore it may have been expected that those who were already distressed in the laboratory studies may have been less susceptible to the experimental conditions where ACT components were used, thereby less likely to show a positive change. However, it is important to recognise that laboratory studies differ from general outcome studies and only specific components of psychological inflexibility were targeted which may be why no differences between the groups were found. In addition, it is unclear how the distressed group were classified as some studies involved individuals who were previously depressed or who had elevated depression, which may not have been at a clinical level. A criticism of laboratory studies can be their generalisability to clinical populations as they involve discrete processes; however their usefulness is in exploring and testing theories which can then be applied to clinical populations. A key finding of Levin et al’s. study which may apply directly to clinical populations was that experiential conditions lead to greater positive results compared to rationale conditions.

Due to concerns that reviews into ACT were become focused on discrete issues such as methodology quality rather than evidence for its effectiveness Ruiz (2010) conducted a review of ACT studies in order to follow-up from Hayes et al’s. (2006) earlier work. Similarly to Hayes et al. (2006) Ruiz examined the research based on type of study e.g. correlational, laboratory or outcome study. The results of the
review indicated that the AAQ correlated positively with depressive and anxiety symptoms (r=55, r=52 respectively).

Similarly to Levin et al. (2012) Ruiz reviewed experimental laboratory studies, also finding that the components of ACT such as experiential avoidance did impact on psychological functioning. However, as Ruiz conducted a review the results are descriptive regarding the research and it is not noted whether the differences found were significant or not. Similarly to other studies reviewing ACT, Ruiz concludes that ACT is showing promise as an effective therapy however notes further studies are required. Drawing on the review of AAQ correlational studies Ruiz concludes that there is support for the ACT model. As Ruiz’s review is descriptive and re-evaluates a number of studies that have previously been examined in other reviews (e.g. Hayes et al., 2006) it is perhaps time for a more thorough review of the ACT evidence base.

A key element of ACT is that the approach is not specific to people with diagnosable mental health problems but is orientated to ‘broadly defined problems’ (Hayes et al., 2004), although there is evidence it still remains applicable to mental health conditions. This is of relevance to the current study, as mentioned previously; carers by default of their caring role will not necessarily have a diagnosable mental health problem. Rather they are more at risk of developing anxiety or depression and may experience higher levels of distress than the general population.

A recent study (Fledderus et al., 2010) highlights how ACT and mindfulness together may benefit people who have mild to moderate distress levels. Their study examined a total of 93 participants, who were deemed to be within the mild to moderate range of psychological distress through screening interviews. Participants completed eight sessions of a “living to the full” group programme and were compared to a wait-list control group. The results indicate that the ACT and
mindfulness intervention significantly improved the treatment groups’ mental health by the end of the group and at five month follow up. In addition emotional and psychological well-being improved as did psychological flexibility, indicating the ACT protocol was successful (Fledderus et al., 2010). This study indicates that ACT and mindfulness may be potentially beneficial in improving outcomes, particularly well-being, in individuals who have lower levels of psychological distress. A criticism of the study is that it is unclear the extent of participants’ mental health difficulties. While the aim of the study was to examine the use of the intervention as a health promotion tool, participants were recruited from other psychologists, indicating that some participant’s distress may have been quite marked as they were already seeking treatment. As there was no structured screening of participants, face-to-face screening was used, it is not clear that those with high levels of distress, or no distress would have been adequately screened out. As an initial study though the results are interesting and demonstrate the wider application ACT may have, which includes its potential usefulness with carers.
### Table 1.2

**Summary of ACT papers reviewed**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Sample Size</th>
<th>Design/Analysis</th>
<th>Results</th>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hayes <em>et al.</em> (2006). Acceptance and Commitment Therapy: Model, processes and outcomes.</td>
<td>N=704, from 12 studies</td>
<td>Meta-analysis</td>
<td>Results indicated a medium effect size for ACT when compared to other treatment conditions. Effect sizes were large when ACT was compared to treatment as usual, wait-list or placebos.</td>
<td>Examines ACT in a number of ways from RCTs, experimental designs and correlation of the AAQ to other measures.</td>
<td>Unclear how articles were selected. Research is conducted by proponents of ACT. Limited information is given about the studies included. Not all treatment comparisons are against established psychological treatments.</td>
</tr>
<tr>
<td>Levin <em>et al.</em> (2012). The impact of treatment components suggested by the psychological flexibility model: a meta-analysis of laboratory-based component studies</td>
<td>N=66 studies.</td>
<td>Meta-analysis</td>
<td>Results indicated that the components of psychological flexibility impacted on psychological outcomes and outcomes drive by ACT theory. There is evidence that</td>
<td>Collates and analyses the evidence from a number of studies to assess the theory behind ACT to provide support for the model, firming up the theory. Provides</td>
<td>No rating of methodological quality was completed. While 66 studies were included the number analysed per question was often significantly less due to the categorisation methods used. Risk/distress sample not transferable to</td>
</tr>
</tbody>
</table>
psychological flexibility acts differently on outcomes compared to differing concepts (e.g. fusion). Psychological flexibility has a greater impact when it includes experiential exercises rationale.

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Type</th>
<th>Findings</th>
<th>Limitations</th>
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</thead>
<tbody>
<tr>
<td>Øst (2008). Efficacy of the third wave of behavioral therapies: a systematic review and meta-analysis.</td>
<td>N=13 studies</td>
<td>Meta-analysis</td>
<td>Results indicated a medium effect size for ACT. Criticised the quality of ACT studies and found ACT not to fulfil the criteria for an empirically evidenced treatment. Using an established criteria to rate efficacy. Highlights areas for improvement for ACT studies.</td>
<td>Comparison of studies of ACT against CBT, which has more studies available due to the length of time it has been established.</td>
</tr>
<tr>
<td>Powers et al. (2009). Acceptance and commitment therapy: a meta-analytic review.</td>
<td>N=18 studies</td>
<td>Meta-analysis</td>
<td>ACT treatments showed significant effects compared to control conditions, placebos and TAU, but not when target group not met. Review not completed by a developer of ACT.</td>
<td>Small N of studies, some of which would not be clinically relevant e.g. math anxiety, worksite stress.</td>
</tr>
</tbody>
</table>
diagnosable e.g. math anxiety. No evidence of ACT being more effective than established treatments.

| Ruiz (2010). A review of acceptance and commitment therapy (ACT) empirical evidence: correlational, experimental psychopathology, component and outcome studies. | N is unspecified as no analyses were undertaken and no description of study selection was given. | Descriptive review |
1.12 Mindfulness and ACT Based Carer Interventions

As the current study is investigating mindfulness, psychological inflexibility and valued living in carers a search was conducted to determine if any investigation of these constructs in carers had been done. A literature search was conducted using the following databases: PsychINFO, MEDLINE, EMBASE, OVID, Web of Knowledge and the Cochrane library. For the mindfulness and carer literature search the following key words were used: mindfulness OR mindfulness based stress reduction OR mindfulness based cognitive therapy OR MBSR OR MBCT. These were then combined with: caregiver OR carer OR unpaid carer OR informal carer. Five relevant studies were found which evaluated the use of mindfulness based interventions in unpaid carers. One was unavailable for review as it was in Spanish, though the results are reported elsewhere (Franco et al., 2010). For the literature search into ACT based interventions the following key words were used: acceptance and commitment therapy OR ACT. These were then combined with: caregiver OR carer OR unpaid carer OR informal carer. No relevant papers on the use of ACT in unpaid carers were found. For both searches references of relevant papers were hand searched, but no additional papers were found.

1.12.1 Mindfulness Carer Interventions

Oken et al. (2010) compared a mindfulness based intervention with an education intervention and a respite intervention for 31 dementia caregivers using ANCOVA. However, only 28 out of the initial 31 carers completed the study, so the results need to be interpreted with caution as assuming a medium effect size the study is underpowered (β=0.09). Twenty carers were randomised into the mindfulness and respite groups, ten carers each, with the remaining eleven entering the education group. A wide number of outcome measures were used including measurement of depression, caregiver stress and coping strategies. The results indicate that there were no differences between the education and mindfulness groups on any of the pre- and post-intervention measures. The main outcome measure was the reaction scores from the Revised Memory and Behaviour Problems Checklist (Teri et al., 1992). Both the education and the mindfulness intervention group showed significant improvements in these measures compared to the respite only group. An interesting finding was that
the measures of mindfulness (Mindful Attention Awareness Scale and the non-judgement scale from the Five Facet Mindfulness Questionnaire; Brown & Ryan, 2003; Baer et al., 2006) showed no change during the intervention period, indicating that the intervention did not enhance mindfulness as measured by these scales.

A strength of Oken et al.’s study (2010) is the use of active control groups as this has been neglected in previous mindfulness research. Unfortunately these were not fully controlled as the mindfulness group also attended an education session with the education intervention group. It is possible that the education group and/or group support lead to the positive change, particularly as it is not clear that mindfulness was the critical part of the intervention due to no change being shown on the mindfulness measures. The mindfulness and the education group did not differ on the outcome measures which may be suggestive that non-specific effects that result from being in a group were of importance. It is difficult to assess accurately as there was no support-only control. The actual mindfulness intervention was modified from MBSR and MBCT. The course comprised of six weekly 90 minute sessions and while home practice was encouraged there appears to have been no guidelines to the length of this, or measurement of adherence. The reasons for modification of the programme were only partially based on group need, as it was considered a two hour separation from the care-recipient may lead to an increase in burden (Oken et al., 2010). Though there was no evidence given for that viewpoint. However, the modifications were done to align the intervention group more with the control groups in terms of length of total intervention and each intervention session. The modifications may have made a difference to the informal carers’ ability to learn mindfulness and to benefit fully from the programme. There is a suggestion that this could have been the case as the mindfulness intervention group did not improve on the mindfulness measures. A competing theory is that the intervention did not actually teach mindfulness. This highlights the importance of consistently measuring mindfulness in studies so comparisons can be made and the efficacy of the intervention in teaching mindfulness can be assessed. Also, participants may have just been beginning to cultivate mindfulness and, as it is an ongoing process rather
than a dichotomous state, measurement over time may have been more likely to show significant changes.

An interesting finding from the pre-intervention measures was the correlation of mindfulness measures with the depression and perceived stress measures (Oken et al., 2010). This provides further support that mindfulness is potentially relevant to depression and stress in carers, which is what the current study is attempting to determine (See section 1.10.4).

Epstein-Ludlow et al. (2011) studied mindfulness based stress reduction in caregivers of older adults who either had dementia or were frail due to a severe medical condition. As with comparative studies the sample size was inadequate with nine participants and there was no control group. Therefore results need to be interpreted with caution. Similar to Oken et al.’s (2010) study Epstein-Ludlow and colleagues also modified the format to eight weekly 90 minute sessions with 30 minutes of home practice and no retreat, it is possible these modifications could have impacted on the results.

The results indicated an effect size of 0.29 (Cohen’s $d$) for treatment of depression indicating a mild improvement. However depression levels returned to baseline at the 12 week follow up, which is in line with other research (Franco et al., 2010 as cited in Epstein-Ludlow et al., 2011). In addition few of the participants initially had clinically significant levels of depression which could be indicative of floor-effects. Particularly as other research supports greater improvement following a mindfulness intervention when higher levels of depression and anxiety were present (Hoffman et al., 2010). Mindfulness, as measured by the Kentucky Inventory of Mindfulness Scales (Baer et al., 2004) did not change during treatment. However, individual subscales i.e. acting with awareness, did indicate an increase over time and likewise responses to a question regarding paying careful attention to activities on the SF-12
(Ware et al., 1996) showed an increase. Positive findings of the study were that levels of burden and perceived stress showed improvement after treatment and at follow-up. Qualitative reports from the participants were also positive. The results suggest that mindfulness may be potentially beneficial in reducing perceived stress and burden. Qualitative reports indicate that carers found the mindfulness intervention helpful even if the mindfulness measures did not change, suggesting that mindfulness interventions for informal carer’s merits further research.

McBee (2003) briefly reports on her work delivering mindfulness based interventions to informal carers. The care-recipients resided in a nursing home so the carers’ delivery of care to their friend/relative would likely have been to a different extent to carers where the care-recipient lives independently. McBee’s (2003) study was solely descriptive as no qualitative analysis was done on the carers spontaneous reports. However, from self-report carers in the study did appear to find the mindfulness group and techniques beneficial. Unfortunately, as no analysis was carried out the evidence that this study provides is extremely limited as it is just descriptive.

The following two studies are from poster presentations therefore information regarding the studies and the exact type of mindfulness interventions is limited. A recent study into the use of mindfulness in people with Parkinson’s disease and their partners indicated that mindfulness may be related to lower anxiety and depressive symptoms as measured by the Beck Anxiety Inventory and the Beck Depression Inventory (Dreeben et al., 2011). A positive association between mindfulness and sleep quality was also found. While this study mentions family members serving as carers it is unclear from the abstract whether all patient/partner dyads involved a partner undertaking a caring role or what exactly the intervention was. Ho et al. (2011) examined MBSR in Alzheimer carers. Their results indicated a significant improvement in psychological status as measured by the Caregiver Self Assessment
Questionnaire. Again it is unclear how the intervention was delivered and full details of the carer sample were not available.

From the studies available it seems that more work is required in assessing whether mindfulness could be a potentially beneficial for carers. Evidence from other studies (non-caring population) suggests it is a potentially useful intervention. More research is required to assess if mindfulness is linked to the caring role. The current study aims to do this by assessing if mindfulness is associated with distress and well-being in carers and if it can moderate this relationship. This is important to examine as if there was a link it would provide further rationale for studying mindfulness interventions in carers.

1.12.2 ACT Interventions for Carers
While the literature search yielded no papers on the use of ACT in unpaid carers, there were papers of the use of ACT in paid carers. While there are clear differences between paid and unpaid carers such as monetary value, paid carers being able to leave either permanently or at the end of a shift, employer support etc. the relevant papers were still reviewed.

Noone and Hastings (2010) conducted a group intervention entitled Promotions of Acceptance in Carers and Teachers (PACT) for paid carers of adults with a learning disability. Two trials were run giving a combined sample size of 34. The results indicate that care staff’s psychological well-being (as measured by the General Health Questionnaire) improved even though the amount of perceived stressors (as measured by the Staff Stressor Questionnaire) in work had not decreased. The authors hypothesise that this is due to the staff, as a result of the training, defusing more from their thoughts and engaging in less experiential avoidance (Noone & Hastings, 2010). In addition, they acknowledge that the values work may have resulted in staff reflecting on how their work role fits with how they are choosing to live their life. While the roles of paid and unpaid carer are similar with regard to the
tasks undertaken there are significant variations in the role. For example, paid carers are unlikely to be related to the person they care for, which probably impacts on their emotional investment. In addition, they receive protection due to employment regulations and are financially reimbursed for the work they undertake. Nevertheless, the results from Noone and Hastings study (2010) are interesting and highlight that mindfulness and ACT interventions may be of importance to unpaid carers.

A more recent study examined ACT with staff working with people with learning disabilities (Bethay et al., 2012). They compared ACT and applied behaviour analysis (ABA) training against ABA training alone. Unfortunately, their hypothesis that the ACT plus ABA intervention would result in greater changes in psychological distress and risk of burnout was unsupported. Further exploration of their results indicate that if participants had greater distress levels on the GHQ-12 then those in the ACT plus ABA group did show a significant reduction in distress. However, there are issues with their results, specifically due to the small total number of participants (N=34), which when broken down into the higher distress groups only gives a sample size of 14. This sample is unevenly distributed to the ABA control group, nine against five in the ACT group. Therefore, the control group had more participants who were distressed which may explain the greater reduction over time in the ACT group. The sample Bethay et al. (2012) used differed from Noone and Hastings study (2010) as it contained few direct care staff and the majority of participants were psychologists or psychology technicians (N=25). The different roles of psychologists and higher levels of training and supervision compared to carers may explain some of the differing results when compared to Noone and Hastings (2010). It could be hypothesised that the psychologists in the study may already have been using ACT techniques as part of their therapeutic range and as such the training would not have added anything additional to their skills. Screens of psychologists own ACT practice would have been helpful in this case. Also as the intervention comprised of ACT plus ABA and ABA alone it would be helpful to also have separate ACT training group so full comparisons can be made.
The evidence base currently though is weak and as Noone and Hastings (2010) and Bethay et al. (2012) recognise their studies are not without fault, for example small sample size, no control study and no measurement of acceptance or mindfulness. As the research is in its infancy these are areas that can be improved on in the future. It is hoped that the current study may add to the emerging research in this area by demonstrating that carers whose caring role is in line with their values, have lower psychological inflexibility and who are more mindful may experience greater well-being and less distress than those who do not, even if the level of subjective stressors are at a similar level.

It was drawn to the author’s attention that Márquez-González et al. (2010) were developing an ACT intervention framework for carers of individuals with dementia. This framework is based on the principles of ACT through acceptance of internal and external events, while not aiming to control, change or avoid. It is specific to carers as the focus is on the positive aspects of caring, which is hypothesised to be an area carers overlook when coping with the difficult aspects of the role. As such the intervention focuses on re-connecting the caring role with carer’s values. Márquez-González et al. explored their framework through a pilot study specific to a Spanish population. It comprised of 16 carers split equally into the ACT intervention group and a non-specified control group. Carers were compared on measures of depression, anxiety and the experiential avoidance in caregivers questionnaire (EACQ). The EACQ is a modified version of the AAQ to examine experiential avoidance within a carer population. However, this measure has not been fully validated so results based on this need to be considered with caution. The results of the study indicated that carers in the ACT intervention had a significant decrease in experiential avoidance. No other significant findings were found. The study did not measure values, but it may have been interesting to do this as a focus of the intervention was on the carer’s values. The use of ACT as a carer intervention is in the early stages of development as shown by the lack of research in this area. However, research is starting to develop and Márquez-González et al’s. study is
interesting as it is one of the first to consider this area and further investigation into their ACT framework is warranted.

1.13 Overall Summary
Research has indicated that informal carers are at risk of a number of negative outcomes as a result of their caring role (e.g. physical health problems, anxiety, depression and financial difficulties). Current models of caring do not adequately explain outcomes of the caring role and in particular neglect the positive outcomes that have been described by some carers. Research has indicated that stressors (burden) related to the caring role do not necessarily lead to negative outcomes, however there has not been an adequate explanation of what other factors may be important in leading to negative outcomes. Research indicates that certain ways of coping such as finding meaning and being intrinsically motivated may moderate some of the effects, though this has not been fully explored. Interventions for informal carers have a mixed evidence base and have generally been of poor methodological quality. One criticism has been the lack of theoretical knowledge behind the development of interventions which means they are untargeted in their approach. It may be that examining carers who report positive outcomes from their caring role may give suggestions as to what factors may be important in moderation between distress and poorer outcome, or burden and poorer outcome. Newer psychological interventions of mindfulness and ACT may be potentially important in moderating some of the negative effects of informal care-giving.

Although research has not yet examined the relationship between mindfulness and ACT processes in informal carers, based on earlier work on meaning, coping and motivation it could be expected that these processes could explain some of the relationship between burden and outcome. The current study aims to investigate this.
1.14 Aims of the Current Research
The current study aims to investigate whether a carer’s level of psychological inflexibility, mindfulness and the extent to which they live in accordance with their values moderates the relationship between distress and well-being and burden and well-being. This is to try and establish whether these factors may be potentially useful in understanding aspects of the care-giving experience and which may be protective of good well-being. If this is established it could potentially assist in the development of interventions for distressed or burdened carers.

Firstly, the study will investigate whether mindfulness, psychological inflexibility and valued living moderate the relationship between distress and well-being. Secondly, the study will examine whether mindfulness, psychological inflexibility and valued living moderate the relationship between burden and well-being. In addition, relationships between mindfulness, psychological inflexibility and valued living with distress and wellbeing and burden and well-being will be explored separately.

1.15 Hypotheses
**Hypothesis 1:** Higher levels of mindfulness and valued living will be associated with lower distress. Higher levels of psychological inflexibility will be associated with increased distress.

**Hypothesis 2:** Higher levels of mindfulness and valued living will be associated with higher well-being. Higher levels of psychological inflexibility will be associated with decreased well-being.

**Hypothesis 3:** Mindfulness, psychological inflexibility and the extent to which unpaid carers are living in accordance with their values will moderate the relationship between distress and well-being. **Hypothesis 4:** Mindfulness, psychological inflexibility and valued living will moderate the relationship between burden and well-being.
Chapter 2: Methodology

2.1 Design
The study employed a within-subjects design. The study involved quantitative questionnaires which were completed at one time point.

2.2 Ethical Issues & Approval
The study had two recruitment arms, recruitment through the voluntary sector and recruitment through the NHS. Initially approval was only sought for recruitment through the voluntary sector, as it had been anticipated that this would achieve the required sample size. This part of the study was reviewed by the University of Edinburgh’s Clinical Psychology Ethics Review process and permission to proceed with the study was granted. The local NHS ethics committee were contacted and indicated that NHS ethical approval was not required (appendix I).

Due to poor recruitment through the voluntary sector, the recruitment process was re-designed to include recruitment via the NHS. For this part of the study ethical approval was sought and obtained from the local NHS research ethics committee and Research and Development team (see appendix II and III). As part of this the voluntary sector recruitment stream was reviewed. The University of Edinburgh’s Clinical Psychology Ethics Review panel were informed of this change to the study and the subsequent NHS ethical approval.

A key ethical consideration was that as carers may be caring for people with life-limiting conditions there was the potential that a carer may receive a questionnaire pack after the care-recipient had died. To minimise this risk carers were only approached once someone involved with their case had confirmed there had been no bereavement of the care-recipient and that the care-recipient was not near end of life. The project decided not to seek recruitment via other means, such as via post to lists.
of carers held by carer support organisations, in order to reduce the likelihood that recently bereaved carers would be contacted.

The Depression Anxiety and Stress Scale (DASS-21) can identify participants with potentially high levels of distress. Due to this it was decided that should any participant score at the severe level then their GP would be contacted in order to make them aware of the screening score and for further treatment/advice to be provided as appropriate. As participants’ details were not available to the researcher it was not possible to obtain their GP details via NHS records. Instead participants were requested to include their GP details along with their own so the researcher could contact their GP if necessary. Participants were informed about this on the information sheet (appendix IV) prior to consenting to participate in the study. They were also aware that the provision of such details was voluntary. If GP details were not provided the researcher was unable to notify the participants GP. Four participants required a letter to be sent to their GP due to their questionnaire responses.

It was recognised that the questionnaires had the potential to elicit distressing emotions in participants as they would have to consider how their caring role has impacted on them. Participants were advised via the information sheet that they had the right to withdraw at any time and should contact their GP should they feel distressed by any of the questionnaire items.

2.3 Inclusion & Exclusion Criteria
Participants were included in the study if they were over 18 years of age and providing unpaid care to an adult over 18 years of age, who was not at the palliative stage of their condition. There was no minimum amount of time or hours that the person had to provide care for. Carers who were in receipt of carers allowance were able to participate.
2.4 Recruitment
Participants were recruited through four organisations that either work with carers or regularly come into contact with carers; two Clinical Psychology departments within NHS Scotland were also involved in the recruitment process. All of the organisations were contacted by the researcher and provided with verbal and written information about the study. Organisations which agreed to assist with recruitment were provided with questionnaire packs to distribute and the inclusion/exclusion criteria were explained. The organisations involved in the study were located within three Scottish local authority areas.

To protect participants’ anonymity, the organisations cannot be named as some organisations recruited small numbers of participants. A brief description of the organisations involved with the study is detailed in the table below.
Table 2.1

Description of organisations involved in the study (N=56)

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Organisation’s Clients</th>
<th>Number of questionnaire packs distributed/potential participants contacted</th>
<th>Number recruited</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>People with dementia and their carers</td>
<td>95</td>
<td>18</td>
</tr>
<tr>
<td>B</td>
<td>People who have had a brain injury</td>
<td>36</td>
<td>3</td>
</tr>
<tr>
<td>C</td>
<td>All types of unpaid carers</td>
<td>50</td>
<td>16</td>
</tr>
<tr>
<td>D</td>
<td>People with a physical or sensory disability</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>E</td>
<td>People accessing the Neuropsychology or Oncology services within one NHS area.</td>
<td>83</td>
<td>18</td>
</tr>
</tbody>
</table>

2.5 Procedure
The procedure for participants varied dependent on the organisation they were recruited through. For ease of explanation how recruitment took place generally will be explained, followed by organisational differences.

All potential participants were initially screened by voluntary organisation staff or NHS staff to ensure that the care-recipient was not medically unwell or had died. All potential participants had the study verbally explained to them. For organisations A, B, C and E this was done either by staff working directly with the carers or the researcher presenting the study to carer support groups. Organisation D does not work directly with carers, but works with individuals who are likely to have carers. For this organisation questionnaire packs were left in the waiting area and staff,
when they came into contact with carers meeting the study’s criteria, discussed the study with the carers. Recruitment in organisation B also involved a staff member (whose role is to directly work with carers) emailing the information sheet to carers on their distribution list, whom they were able to confirm, had not been recently bereaved. There were two separate psychology departments in organisation E and recruitment was identical to organisations A-C however, one of the departments also sent an invitation letter and information sheet to known carers who had been involved with the department recently. The carers then contacted the researcher directly if they wished to participate in the study.

The questionnaire packs included a participant information sheet, prize draw information sheet (please note for recruitment that took place after NHS ethical approval had been sought, there was no prize draw), an envelope for prize draw information, the outcome measures and a stamped addressed envelope for the return of the questionnaire pack. The outcome measures were collated together into a pack along with instructions for completion and the researcher’s contact details. On the front of the pack there was an individual hand written note, thanking participants for taking the time to consider participating in the study.

2.6 Outcome Measures
Questionnaires were used to measure distress, burden, well-being, psychological inflexibility, mindfulness and valued living. A demographic questionnaire was also included.

2.6.1 Demographic Questionnaire
Carers were asked to complete demographic information relating to their age, gender, employment status, relationship to care-recipient, time spent providing care and type of care provided. In addition they were also requested to provide some information regarding the care-recipient, including diagnosis, age and gender. The demographic questionnaire included a five-point Likert scale asking carers to provide a subjective
rating of how stressful they find their caring role. The demographic questionnaire is included in appendix V.

### 2.6.2 Warwick Edinburgh Mental Well-being Scale

The Warwick Edinburgh Mental Well-being Scale (WEMWBS) is a well-being measure initially developed from the New Zealand Affectometer 2 (Tennant et al., 2007). The scale contains fourteen statements and participants are asked to rate to what extent they have felt that way over the past two weeks. Ratings are completed on a five point Likert scale, with one representing none of the time and five representing all of the time. Scoring is completed by totalling all the scores and a higher score equals a higher level of well-being.

Test-retest reliability at one week was good at $\alpha = .83$ (Tennant et al., 2007). Compared to other well-being measures it appears to be less prone to social desirability responding (Tennant et al., 2007). The WEMWBS appears to have good face validity and good criterion validity when compared against existing measures. Confirmatory Factor Analysis indicates that the WEMWBS had adequate construct validity (Tennant et al., 2007). Internal reliability was high as well at $\alpha = .89$. There was some suggestion of redundant items on the scale as Cronbach’s alpha only fell below .8 after six items had been removed, suggesting some questions are highly correlated and may be measuring the same construct. These items are still present in the current version of the measure used in this study.

Later analysis provided evidence for reducing the scale to seven items (Stewart-Brown et al., 2009) and created the Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS). As the researcher did not have this information available when the current study was designed and the long form is still widely used, continuation of the use of the long form was considered appropriate. The correlations between the SWEMWBS and the WEMWBS are large at $r=0.945$ (Stewart-Brown et al., 2009). In addition, while the evidence for the use of the short form appears adequate, the
short form has not been studied using a population sample. Rather the data from the original WEMWBS study was used and analysed as the short form items are embedded in the long form. Therefore information about the acceptability of the short form to participants is unknown as well as its criterion or face validity as this was not assessed. As Stewart-Brown et al. (2009) concluded that there were no reasons not to continue with the longer form the current study proceeded with the original 14 item scale.

2.6.3 Depression Anxiety and Stress Scale (DASS)
The DASS-21 consists of 21 items that correspond to the three subscales of depression, anxiety and stress (Lovibond & Lovibond, 1995). Participants are required to rate on a four point scale the extent to which each statement has applied to them over the past week. The DASS-21 can be scored by totalling scores for the separate depression, anxiety and stress subscales and also by totalling the total score which is conceptualised as a general dimension of psychological distress. Higher scores on each subscale are indicative of a higher level of depression, anxiety or stress and there are various cut-off points to indicate level of severity.

The DASS-21 was chosen over the DASS-42 as research indicates it had superior discriminant validity (Henry & Crawford, 2005). In addition it is shorter to administer and has adequate reliability and validity.

For the total scores the DASS-21 shows excellent reliability at $\alpha = .93$ for the total score and $\alpha=.88, .82, .90$ for the depression, anxiety and stress subscales respectively. The current study will use the total score as an indication of psychological distress. The literature indicates that the DASS-21 has good validity (Henry & Crawford, 2005).
2.6.4 Acceptance and Action Questionnaire - second version
The Acceptance and Action Questionnaire – second version (AAQ-II) is a seven item measure of psychological inflexibility. The AAQ-II has good reliability ($\alpha = .84$) and good test-retest reliability at 3 and 12 month intervals ($\alpha = .81$ and $\alpha = .79$ respectively). Confirmatory factor analysis confirmed that the scale measured a single factor labelled as psychological inflexibility, CFI >.95 (Bond et al., 2011). The AAQ-II scores range from 7 to 49, with higher scores representing a higher level of psychological inflexibility.

Overall the AAQ-II demonstrated good validity in that it correlated with measures of thought suppression (convergent validity) and it correlated with measures of psychological distress (construct validity). The current study uses the most recent 2011 version of the AAQ-II.

2.6.5 Zarit Burden Interview
The Zarit Burden Interview (ZBI) is a widely used measure of caregiver burden (Zarit et al., 1980). It was originally a 26 item measure but it is the modified 22 item version which is commonly used. The ZBI contains 22 items and participants are required to respond on a five point scale to what extent the statements reflect how they feel about caring. Higher scores are indicative of higher burden.

A recent systematic review found the ZBI to be the best available measure of burden (Whalen & Buchholz, 2009). The 22 item scale loads on two factors; personal strain and role strain (Herbet et al., 2000). These could be hypothesised as linking onto subjective (personal strain) and objective (role strain) burden. Internal reliability of the ZBI was excellent at .92. Herbet et al.’s. (2000) study specifically examined dementia caregivers and it was this purpose that the ZBI was initially developed for. However, studies have used the ZBI for other carer groups and it has been found to have excellent internal consistency at $\alpha > .90$ (Phillips, 2001; Uttl, 1998). Good validity has also been found across studies (Cifu et al., 2006; Phillips et al., 2001,
Uttl, 1998) and it is a well used measure within carer literature which should allow for comparison of this study’s findings with other literature.

2.6.6 Five Facet Mindfulness Questionnaire
The Five Facet Mindfulness Questionnaire (FFMQ) was developed from factor analysis of existing mindfulness measures which resulted in the identification of five factors of mindfulness (Baer et al., 2006). The FFMQ scales use these factors to measure mindfulness. The FFMQ consists of 39 items and participants have to rate each item on a five point scale as to how true the statement is to the individual.

Exploration of the FFMQ has found its scales to have good to excellent internal consistency ranging from $\alpha = .75$ to $.91$ (Baer et al., 2006). In addition it has been found to have good construct validity (Baer et al., 2008). The current study used both the total score from the FFMQ to give an overall score of mindfulness and the separate subscale scores to measure the different aspects of mindfulness.

2.6.7 Valued Living Questionnaire
The Valued Living Questionnaire (VLQ) was developed to assess valued living within an ACT framework (Wilson et al., 2010). It is designed to measure the extent to which an individual lives in line with their chosen values in everyday life. It aims to assess which values are uniquely important to an individual and the extent they are currently living in accordance with their important values. The questionnaire has two parts. The first requests participants to rate how important ten different domains are to them on a ten point scale. This is the importance subscale. The second part of the questionnaire asks participants to rate how consistently their actions/behaviours over the last week have been with their values. This is the consistency subscale.

The ten domains assessed by both parts of the questionnaire are:-

- Family (other than parenting and marriage)
- Marriage/couples/intimate relations
• Parenting
• Friendships/social relations
• Employment
• Education/training
• Recreation
• Spirituality
• Citizenship/community life
• Physical well-being

Responses from both the importance and consistency scales are used to calculate a valued living composite score. This composite score is used to assess the extent that an individual is living in line with their values in everyday life. It is this score which will be used as a measure of valued living.

Test-retest reliability of the VLQ was good (.75). Internal consistency was also good for the separate importance and consistency subscales (.77 and .75 respectively) and acceptable for the valued living composite score (Wilson et al., 2010), which is the version the current study has used.

2.7 Statistical Analysis
Regression analysis was completed to investigate the relationship of the independent variables on levels of distress and well-being. Six moderated multiple regressions (Baron & Kenny, 1986) were completed; three to examine whether levels of mindfulness, psychological inflexibility and valued living moderated the relationship between distress and positive wellbeing. A further three were completed to examine whether mindfulness, psychological inflexibility and valued living moderated the relationship between burden and level of distress. The results were analysed using SPSS for Windows, Version 19.
2.7.1 Power & Sample Size  
Regression analysis was used to explore the effect of the moderator variables on the relationship between the predictor and criterion variables. As the moderator (predictor) variables function as independent variables, two independent variables were included in each analysis (Baron & Kenny, 1986). In order to obtain adequate power of 0.80, \( \alpha = .05 \) for multiple regression analysis, \( N \geq 50 + 8m \), where \( m \) is the number of IVs, is required (Green, 1991). For the current study with two independent variables in each regression analysis, the sample size required would be \( 50 + (8)(2) = 66 \).

Using G*Power to calculate the required sample size, with a medium effect size and adequate power of .80, then a total sample size of 68 participants would be required. The current study recruited a sample of 55, therefore post-hoc analyses indicate that the study is underpowered at 0.70 increasing the likelihood that a type II error could have occurred.

2.7.2 Missing Data  
There were some cases with incomplete data for the outcome data. The individual mean across items was calculated and applied to the incomplete scores (Tabachnick & Fidel, 2009). Where possible subscale means were also checked along with the total score mean to ensure the best score was obtained.
Chapter 3 - Results

This section shall describe the main results derived from the data and the analyses undertaken for each hypothesis.

3.1 Characteristics of the Sample
278 questionnaires were distributed and 56 were returned (20% response rate). One participant was excluded as they did not meet the inclusion criteria (care recipient was under 18 years of age), making the total number of participants 55. The genders of the participants are presented in Table 3.1. Their ages ranged from 41 to 83 years of age, with a mean age of 59 years. The age of the care-recipient ranged from 22 to 89 years of age, with a mean age of 65 years. The highest percentage of respondents had been caring for 5-10 years (36%). The highest percentage of respondents provided on average 100+ hours of care per week (42%).

Table 3.1
Participants gender (N=55)

<table>
<thead>
<tr>
<th>Carer N</th>
<th>Carer %</th>
<th>Care-recipient N</th>
<th>Care-recipient %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>13</td>
<td>24%</td>
<td>36</td>
</tr>
<tr>
<td>Female</td>
<td>42</td>
<td>76%</td>
<td>19</td>
</tr>
</tbody>
</table>

Table 3.1 indicates that the carer sample had a high proportion of female carers. Conversely a large number of the care recipients were male.

The most common diagnosis for care-recipients in this sample was dementia (39%), the remaining diagnoses were neurological condition (35.8%), cancer (13%), physical or mental health condition (7.5%) and learning disability (3.7%). 47% of care-recipients had multiple diagnoses, the first reported diagnoses was taken to be the main presenting problem.
Further demographic characteristics of the participants are presented in Table 3.2.

Table 3.2
*Participant’s relationship with carer and employment status (N=55)*

<table>
<thead>
<tr>
<th>Relationship to care-recipient</th>
<th>Wife</th>
<th>Husband</th>
<th>Daughter</th>
<th>Other familial Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wife</td>
<td>23 (42%)</td>
<td>9 (16%)</td>
<td>10 (18%)</td>
<td>13 (24%)</td>
</tr>
<tr>
<td>Husband</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other familial Relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment status of caregiver</th>
<th>Employed</th>
<th>Unemployed</th>
<th>Retired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>18 (33%)</td>
<td>6 (11%)</td>
<td>31 (56%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lives with care recipient</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>40 (72%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>15 (27%)</td>
<td></td>
</tr>
</tbody>
</table>

Table 3.3 shows the number of carers’ who scored above the clinical cut-off points for the Depression, Anxiety and Stress Scale (measure of distress) and the Zarit Burden Interview (level of burden), which could be indicative of them experiencing above moderate levels of distress, anxiety and depression and high levels of burden.

For the distress measures, the cut off points for moderate depression, anxiety and stress were used (Lovibond & Lovibond, 1995). For the burden measure a cut-off point of 24 was used (Schreiner et al., 2006).
Table 3.3

Number of carers scoring above the cut-off points on the Distress (DASS) and the Burden (ZBI) Measures (N=55)

<table>
<thead>
<tr>
<th></th>
<th>Depression</th>
<th>Anxiety</th>
<th>Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress</td>
<td>23 (42%)</td>
<td>16 (29%)</td>
<td>15 (27%)</td>
</tr>
<tr>
<td>Burden</td>
<td>48 (87%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.2 Assumptions of Regression Analysis

Prior to completing moderated multiple regression analysis the data was screened to ensure the assumptions of regression were met.

To check whether the scores obtained were normally distributed the Kolmogorov-Smirnov test was used. The results indicate distress (D(55) = 0.126, p=0.029), and psychological inflexibility (D(55) = 0.150, p=0.003) were significantly non-normal. To test the distribution of the data the skewness and kurtosis of distress and psychological inflexibility were examined. Converted to z-scores, to compare against the values that would be expected by chance, only distress was significantly skewed at p<.01 (Z = 2.38). Indicating a significant number of low scores in the distribution. Boxplots were examined and no outliers were found. While it is known the Depression Anxiety and Stress Scale does have a positive skew, likely to represent population biases towards non-depressed, as an assumption of regression analysis is that data is normally distributed, the depression data was transformed using square root. Re-examination of the transformed data using the Kolmogorov-Smirnov test indicated that distribution of distress scores did not significantly differ from a normal distribution, D(55) = 0.059, p = 0.02.

Following the transformation of distress scores, the assumptions for a regression analysis were met for the models tested. The variance inflation tolerance was within normal limits, indicating no evidence of multicollinearity. Multicollinearity was also
assessed using a Pearson product-moment correlation, the results of which are reported in Table 3.4. Histograms and P-Plots of the residuals were examined which indicated that they were normally distributed and there was no evidence of homoscedasticity or linearity. The standardised residuals were examined and two cases were found to have a standardised residual above three. On further exploration of Cook’s distance, average leverage and Mahalanobis distance there was no evidence to suggest that there were influential cases within the data.

**Table 3.4**

*Correlations between variables (N=55)*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Distress</th>
<th>Valued Living</th>
<th>Well-being</th>
<th>Psychological Inflexibility</th>
<th>Mindfulness</th>
<th>Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress</td>
<td></td>
<td>-.530**</td>
<td>-.612**</td>
<td>.679**</td>
<td>-.419**</td>
<td>.656**</td>
</tr>
<tr>
<td>Valued Living</td>
<td>.583**</td>
<td></td>
<td>-.460**</td>
<td>.338*</td>
<td></td>
<td>-.414**</td>
</tr>
<tr>
<td>Well-being</td>
<td>-.373**</td>
<td>.411**</td>
<td></td>
<td></td>
<td></td>
<td>-.439**</td>
</tr>
<tr>
<td>Psychological Inflexibility</td>
<td>-.401**</td>
<td></td>
<td></td>
<td></td>
<td>.489*</td>
<td></td>
</tr>
<tr>
<td>Mindfulness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-.241</td>
</tr>
</tbody>
</table>

**Significant at 0.01 level; *Significant at 0.05 level**

The correlations indicated that a number of the predictor variables were significantly correlated. Using Cohen (1992) as a guide, large effect sizes were found for the correlations between distress and wellbeing (r=-.612, p<0.001); distress and valued living (r=-.530, p<0.001); distress and psychological inflexibility (r=.679, p<0.001); distress and burden (r=.656, p<0.001) and valued living and wellbeing (r=.583, p<0.001). The remaining correlations showed medium effect sizes.

High inter-correlation between the predictor variables is potentially problematic for a regression analysis as it suggests potential multicollinearity between the variables.
used in the model. The potential implication for a regression analysis is that when
two correlated variables are used it is difficult to determine which variable is the
most important i.e. which variable accounts for the most unique variance. This is
because highly correlated variables are measuring partly the same thing and as they
change in line with each other it is hard to identify which of the variables is the most
important. If two, or more, highly correlated predictors are used in the analysis, it
limits the model as it means there is little unique variance when the correlated
predictors are added to the model, and the model is likely to contain some redundant
variables. The coefficient of determination was calculated for all significant
correlations to assess the amount of shared variance between variables. The greatest
amount of shared variance was found for the relationship between distress and
psychological inflexibility ($r^2=0.46$), which indicates that while they is a strong
relationship between the two predictors they is still a large amount of the variance
which is unaccounted for. The data was explored further to ensure that the
collinearity was not too high. The variance inflation level was examined for each
regression analysis and was not greater than 10 (Myers, 1990). In addition the
variance proportions were explored which indicated that each predictor variable had
most of its variance loading onto different dimensions, suggesting no
multicollinearity in the models.

3.3 Results in Relation to Hypotheses

3.3.1 Hypothesis 1: Higher levels of mindfulness and valued living would be
associated with lower distress. Higher levels of psychological inflexibility would be
associated with higher distress.

The results from the correlation analysis indicate that there was a significant negative
relationship between mindfulness and distress $r = -.419$, $p = 0.002$. There was a
significant positive relationship between psychological inflexibility and distress $r = .679$, $p <0.001$. There was also a significant negative relationship found between
distress and valued living $r = -.530$, $p <0.001$. The results indicate that the hypothesis
is supported with higher levels of psychological inflexibility being related to higher
levels of distress and higher levels of mindfulness and valued living being related to lower levels of distress.

3.3.2 Hypothesis 2: Higher levels of mindfulness and valued living would be associated with higher well-being. Higher levels of psychological inflexibility would be associated with lower well-being.

The results from the correlation analysis indicates that there was a significant negative relationship between psychological inflexibility and well-being $r=-.373$, $p = 0.005$. In addition significant positive relationships were found between mindfulness and well-being, $r=.411$, $p = 0.002$; and valued living and well-being, $r = .583$, $p <0.001$. The hypothesis is supported as mindfulness and valued living were significantly associated with higher well-being, and a significant negative relationship was found between psychological inflexibility and well-being. This indicates when psychological inflexibility is high, well-being is lower.

Hypotheses three and four required analysis of the moderation relationship via multiple regressions. For the analysis the predictor and moderator variables were regressed onto the outcome variable, represented in Tables 3.5 and 3.6 as models 1.1, 2.1 and 3.1. The second step in the analysis involved combining the predictor and moderator variables to create an interaction term and regressing this onto the outcome variable, represented in Tables 3.5 and 3.6 as models 1.2, 2.2 and 3.2. If the interaction term proved to be significant, once the preceding variables were controlled for, then this is evidence that the hypothesised moderator variable has moderated the relationship between the predictor and outcome variables. Prior to running the regression the moderator variables were centred by subtracting the sample mean from individual scores on each variable to try and control for multicollinearity (Aiken & West, 1991).
3.3.3 Hypothesis 3: *mindfulness, psychological inflexibility and valued living will moderate the relationship between distress and well-being.*

A moderation analysis was carried out using moderated multiple regression to examine the effect of each moderator on the relationship between distress and well-being. Results from the correlation analysis indicate that distress and well-being are significantly negatively correlated, (Table 3.4). The results of the analysis indicate that psychological inflexibility and valued living do moderate the relationship between distress and well-being (Table 3.5) as the results of models 2.2 and 3.2 were significant. Indicating that the moderation variable, the interaction term, did significantly change the relationship between distress and well-being in some way. From Table 3.5, models 1, 2 and 3 are significant, however these models are the predictor (distress) and moderator variables (mindfulness, valued living and psychological inflexibility) regressed on the outcome (well-being) and not the interaction term which is the moderator variable. Models 1, 2 and 3 indicate that the predictor and moderator variables predicted well-being and models 2.2 and 3.2 indicate that the moderator variables changed the relationship between distress and well-being. So their presence changes the relationship between distress and well-being. The results indicate that psychological inflexibility and valued living moderate the relationship between distress and well-being. Therefore the hypothesis is partly supported.
Table 3.5

Results of moderator multiple regression (N=55)

<table>
<thead>
<tr>
<th>Model</th>
<th>B</th>
<th>B</th>
<th>t</th>
<th>R²</th>
<th>Adjusted R²</th>
<th>R² Change</th>
<th>F Change</th>
<th>p</th>
</tr>
</thead>
<tbody>
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<td>Model 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Distress</td>
<td>-2.41</td>
<td>-.515</td>
<td>-4.220</td>
<td></td>
<td>.362</td>
<td>.387</td>
<td>.000**</td>
<td>p&lt;.001</td>
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<tr>
<td>Mindfulness</td>
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<td>.195</td>
<td>1.597</td>
<td></td>
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<td>p=.116</td>
</tr>
<tr>
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<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Distress X</td>
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<td>-.206</td>
<td>-1.817</td>
<td></td>
<td>.426</td>
<td>.391</td>
<td>.039</td>
<td>.075</td>
</tr>
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<td>Mindfulness</td>
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<td></td>
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<td></td>
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<td></td>
</tr>
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<td></td>
</tr>
<tr>
<td>Distress</td>
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<td>-4.472</td>
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<td>.354</td>
<td>.378</td>
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<td>p&lt;.001</td>
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<td>.535</td>
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<td></td>
<td>p=.595</td>
</tr>
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</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distress X</td>
<td>2.881</td>
<td>.301</td>
<td>2.770</td>
<td></td>
<td>.678</td>
<td>.459</td>
<td>.428</td>
<td>.008**</td>
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<td></td>
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<tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distress</td>
<td>-1.87</td>
<td>-.404</td>
<td>-3.319</td>
<td></td>
<td>.436</td>
<td>.457</td>
<td>.000**</td>
<td>p&lt;.05</td>
</tr>
<tr>
<td>Valued Living</td>
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<td>.369</td>
<td>3.027</td>
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<td></td>
<td></td>
<td></td>
<td>p&lt;.05</td>
</tr>
<tr>
<td>Model 3.2</td>
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<td></td>
</tr>
<tr>
<td>Distress X</td>
<td>-1.91</td>
<td>-.210</td>
<td>-2.026</td>
<td></td>
<td>.468</td>
<td>.041</td>
<td>.048</td>
<td>.048*</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

*Significant at 0.05 level

** Significant at 0.01 level
3.3.4 Analysis of Simple Slopes
Due to significant moderator interactions being found between distress, psychological inflexibility and well-being and between distress, valued living and well-being simple slopes analysis was completed. Simple slopes show the relationship between the predictor and outcome variable at low (-1 SD below the mean), moderate (mean) and high (+1 SD above the mean) levels of the moderator. The moderator regression shows that there is a significant moderator interaction between the predictor and outcome variables and the simple slopes allows the direction of this relationship to be examined. The simple slopes are presented below.
Figure 3.1 shows the following:

1. When psychological inflexibility is low, there is a significant negative relationship between level of distress and well-being, $b = -4.18$, $t = -4.57$, $p < 0.001$.

2. At the mean level of psychological inflexibility, there is a significant negative relationship between level of distress and well-being, $b = -2.85$, $t = -3.89$, $p < 0.001$.

3. When psychological inflexibility is high, there is a non-significant negative relationship between level of distress and well-being, $b = -1.52$, $t = -2.00$, $p = 0.06$. 

---

**Figure 3.1**

*Simple plot of well-being, distress and psychological inflexibility*
Figure 3.2

Simple slope of predicted well-being, distress and valued living

Figure 3.2 shows the following:

1. When valued living is low, there is a non-significant negative relationship between level of distress and well-being, $b = -0.92$, $t = -1.61$, $p = 0.11$.

2. At the mean level of valued living there is a significant negative relationship between level of distress and well-being, $b = -1.80$, $t = -3.91$, $p < 0.001$.

3. When valued living is high there is a significant negative relationship between level of distress and well-being, $b = -2.70$, $t = -5.30$, $p < 0.001$. 


3.3.5 Hypothesis 4: mindfulness, psychological inflexibility and valued living will moderate the relationship between burden and well-being.

Moderator multiple regressions were carried out to examine the effect of mindfulness, valued living and psychological inflexibility on the relationship between burden and distress. Table 3.6 details the main results from the models examined. Models 1, 2 and 3 are significant, however these models are the predictor (distress) and moderator variables (mindfulness, valued living and psychological inflexibility) regressed on the outcome (well-being) and not the interaction term which is the moderator variable. Models 1, 2 and 3 indicate that the predictor and moderator variables predicted well-being, but models 1.2 and 2.2 indicated that they do not moderate the relationship between distress and well-being. So the presence of mindfulness and psychological inflexibility does not change the relationship between distress and well-being. However, in model 3.2 the results are significant which indicates that valued living does significantly moderate the relationship between burden and well-being.
Table 3.6

Results of moderator multiple regression (N=55)

<table>
<thead>
<tr>
<th>Model</th>
<th>B</th>
<th>t</th>
<th>R²</th>
<th>Adjusted R²</th>
<th>F Change</th>
<th>p</th>
</tr>
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<tbody>
<tr>
<td>Model 1</td>
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<td>.258</td>
<td>.287</td>
<td>.000**</td>
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<tr>
<td>Burden</td>
<td>-.244</td>
<td>-.354</td>
<td>-.287</td>
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<td>p&lt;.05</td>
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</tr>
<tr>
<td>Mindfulness</td>
<td>.160</td>
<td>.325</td>
<td>2.643</td>
<td></td>
<td>p&lt;.05</td>
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<tr>
<td>Model 1.2</td>
<td>Stressors X</td>
<td>-.119</td>
<td>-.137</td>
<td>1.109</td>
<td>.304</td>
<td>.262</td>
</tr>
<tr>
<td>Mindfulness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model 2</td>
<td>.229</td>
<td>.199</td>
<td>.229</td>
<td>.001**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burden</td>
<td>-.224</td>
<td>-.331</td>
<td>-.239</td>
<td></td>
<td>p&lt;.05</td>
<td></td>
</tr>
<tr>
<td>Psychological Inflexibility</td>
<td>-.229</td>
<td>-.220</td>
<td>-1.563</td>
<td></td>
<td>p=.124</td>
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</tr>
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<td>Model 2.2</td>
<td>Burden X</td>
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<td>.159</td>
<td>1.255</td>
<td>.253</td>
<td>.208</td>
</tr>
<tr>
<td>Psychological Inflexibility</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Model 3</td>
<td>.387</td>
<td>.363</td>
<td>.387</td>
<td>.000**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burden</td>
<td>-.161</td>
<td>-.238</td>
<td>-1.077</td>
<td></td>
<td>p=.053</td>
<td></td>
</tr>
<tr>
<td>Valued Living</td>
<td>.259</td>
<td>.484</td>
<td>4.018</td>
<td></td>
<td>p=.001</td>
<td></td>
</tr>
<tr>
<td>Model 3.1</td>
<td>Burden X</td>
<td>-1.96</td>
<td>-.230</td>
<td>-2.098</td>
<td>.436</td>
<td>.402</td>
</tr>
<tr>
<td>Valued Living</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Significant at 0.05 level

** Significant at 0.01 level
3.3.6 Analysis of Simple Slopes
Due to a significant moderator interactions being found between burden, valued living and well-being simple slopes analysis was completed. The simple slope is presented below.

**Figure 3.3**
*Simple slope of well-being, burden and valued living*

![Graph showing simple slopes analysis](image)

Figure 3.3 shows the following:

1. When valued living is low, there is a non-significant negative relationship between level of burden and well-being, \( b = -0.023, t = -0.34, p = 0.75 \).
2. At mean valued living there is a significant negative relationship between level of burden and well-being, \( b = -0.1606, t = -2.35, p = 0.023 \).
3. When valued living is high, there is a significant negative relationship between level of burden and well-being, \( b = -0.29, t = -3.53, p = 0.001 \).
3.5 Summary of Results
The results indicate that psychological inflexibility and valued living do moderate the relationship between distress and well-being. In addition there was evidence that valued living moderated the relationship between burden and well-being, but mindfulness and psychological inflexibility did not. Therefore hypothesis three and hypothesis four are partly supported. Analysis of the simple plots showed that the moderation relationships were all negative and therefore the moderators strengthened the existing negative relationship between distress and well-being and burden and well-being. An exception may be for valued living, as while the direction of the relationship remains negative, when valued living is high it does not appear to strengthen the relationships between distress and well-being and burden and well-being as much as when it is at mean.

Hypotheses one and two are supported as there are relationships between psychological inflexibility and distress, valued living and distress and mindfulness and distress. A positive relationship between valued living and well-being and mindfulness and well-being was also found and a negative relationship between psychological inflexibility and well-being. The implications of these results will now be discussed.
Chapter 4 - Discussion

This study was designed to examine whether mindfulness, psychological inflexibility and valued living may impact positively on carers' well-being, even in times of burden and distress. Mindfulness, psychological inflexibility and valued living were chosen as potential factors due to the previous research base that suggests they impact on well-being and there is evidence this effect can be present in the general population, without the presence of diagnosable psychological conditions. This may be applicable to a large proportion of the caring population. In addition, the viewpoint of mindfulness and ACT, which psychological inflexibility and valued living is derived from, is that these therapies can be helpful even when the stressor is not changeable. This is hypothesised as being particularly important to carers as often carers do not wish to end their caring role, or have limited choice about being able to end it.

To examine whether the concepts of mindfulness, psychological inflexibility and valued living may be applicable to carers, these were measured in addition to measures of distress and well-being. Relationships between all the variables were examined and moderated regression analysis was carried out to see if mindfulness, psychological inflexibility and valued living change the relationships between distress and well-being and burden and well-being in carers.

The discussion will re-iterate each hypothesis and discuss the relevant results in turn. The clinical implications of the study will then be discussed followed by consideration of the study’s strengths and limitations.
4.1 Discussion of Results

**Hypothesis 1:** Higher levels of mindfulness and valued living will be associated with lower distress. Higher levels of psychological inflexibility will be associated with higher distress.

There was a significant negative correlations found between mindfulness and distress and valued living and distress. A significant positive correlation was found between psychological inflexibility and distress. Therefore both parts of the hypothesis are supported. The results suggest that carers higher in mindfulness or valued living had lower distress levels, and carers higher in psychological inflexibility had higher distress levels. The relationship between psychological inflexibility and distress is also supportive of predictions of the ACT work (Hayes et al., 2006; Bond et al., 2011).

**Hypothesis 2:** Higher levels of mindfulness and valued living will be associated with higher well-being. Higher levels of psychological inflexibility will be associated with lower well-being.

Significant positive correlations were found between mindfulness and well-being and valued living and well-being. Psychological inflexibility was significantly negatively correlated with well-being. Therefore both parts of the hypothesis are supported. The results suggest that carers higher in mindfulness or valued living had greater well-being. Equally carers higher in psychological inflexibility had reduced well-being. These results are supportive of previous research into mindfulness which has also found positive effects of mindfulness training on well-being (Nyklíček & Kuijpers, 2008).

The results of the correlation analyses are interesting as they occur in a population where it is likely no formal training on mindfulness or aspects of ACT has been done. Therefore they highlight that there are variations of the levels of mindfulness, valued living and psychological inflexibility in the general population. This is particularly interesting for mindfulness and ACT as it provides support for the view
that mindfulness is naturally occurring and its presence can impact positively on
distress and well-being (Brown & Ryan, 2003; Hayes et al., 2011). For both
hypotheses the results of the relationship between valued living and distress and
well-being are of particular interest as less work has been done to date on valued
living.

**Hypothesis 3:** *Mindfulness, psychological inflexibility and valued living will moderate the relationship between distress and well-being.*

This hypothesis was partly supported as there was evidence that separately
psychological inflexibility and valued living moderated the relationship between
distress and well-being. However, there was no evidence that mindfulness
moderated the relationship between distress and well-being. The results of the
correlation analysis show that there is a significant negative relationship between
distress and well-being. The moderation showed that this relationship is significantly
changed in some way, by psychological inflexibility and valued living. Examination
of the simple slopes indicated that at low levels of psychological inflexibility the
negative relationship between distress and well-being is strengthened. The direction
of this result was unexpected as while the original hypothesis was non-directional, it
was assumed that if a relationship was present that lower levels of psychological
inflexibility would result in greater well-being compared to higher levels. However,
the moderation analysis is not comparing the difference between low levels and high
levels of psychological inflexibility rather it just shows how the relationship between
distress and well-being changes at low levels of psychological inflexibility, which is
significant; whereas at high levels it is non-significant. The result may represent a
measurement error where low levels (-1SD below the mean) are still capturing
people with greater levels of psychological inflexibility, particularly as it may not
follow that low levels of psychological inflexibility equals psychological flexibility.
This particularly may be the case due to the study’s sample size being small and at
the lower limit of numbers required to do a regression analysis. In addition
examination of the data (Section 3.2) initially indicated that psychological
inflexibility was significantly non-normal, with more scores towards the lower end of
the scale. However, further exploration resulted in the data not requiring transformation.

Valued living was also found to moderate the relationship between distress and well-being. When carers had high levels of valued living well-being was higher. At low levels of valued living there was no change in the relationship between distress and well-being, therefore it is not that carers did worse when valued living was reduced, rather they had better well-being when it was higher. This may suggest that certain levels of valued living may be protective of well-being when distress is present.

Mindfulness was found not to moderate the relationship between distress and well-being. The result indicate that psychological inflexibility and valued living may be important components for carers as they do influence the relationship between distress and well-being significantly.

**Hypothesis 4:** *Mindfulness, psychological inflexibility and valued living will moderate the relationship between burden and well-being.*

The only significant moderation between burden and well-being was found with valued living. Carers who had higher valued living had higher well-being. The relationship is still negative as when burden increases well-being also decreases, therefore at greater levels of burden the relationship between valued living and well-being also decreases, however this is to a lesser extent than when the moderator (valued living) is not present. There was no evidence of psychological inflexibility and mindfulness moderating the relationship between burden and well-being. This could be because there was a smaller significant relationship between burden and well-being than there was between distress and well-being, however for moderation analysis unlike mediation analysis a strong relationship between the predictor and outcome variables does not have to be present. The presence of valued living as a moderator is of particular interest, again because research into valued living has been
more limited, but also because both moderations indicate that valued living influences relationships between well-being, distress and burden in carers. As well-being is used in both moderation analyses it could be that valued living is impacting more on well-being than distress, particularly as it was more highly correlated with well-being than distress.

The results of both moderation analyses are interesting as they go further than saying that a relationship is present. Instead the results give more information on the nature of the relationship and that psychological inflexibility can impact on the relationship distress has with well-being and equally so does valued living, which also impacts on the relationship between burden and well-being.

4.3 Clinical Implications
This study has a number of clinical implications. From the results it is clear that high proportions of the carers sampled have high levels of distress and are heavily burdened. These figures are in line with previous research discussed in chapter one (e.g. Pinquart & Sörensen, 2003) that places carers at risk of a number of negative outcomes. For the current study this would be higher levels of psychological distress, though the results are not comparable to non-carers as this group was not sampled. Clinically carers often do not get their needs met within services, as carers’ needs are not always readily identified; however the current study indicates that carers may be at risk of higher levels of distress and therefore may be in need of support.

The study’s findings may feed back into existing models used to understand carers’ experiences (see section 1.6). With regard to the stress-appraisal model (Hayley et al., 1987) it may not just be the appraisal of the situation as difficult/negative but also attempts to avoid the negative appraisal and/or aspects of the caring role that also feed into carer distress. This is because psychological inflexibility was found to be related to increased distress and carer burden. The current study’s findings that valued living moderated the relationship between distress and well-being and the relationship between burden and well-being could link in to Hayley et al.’s. (1987)
coping response. A carer who is able to continue to live in line with their values and/or incorporate aspects of the caring role into this may have more positive outcomes with regard to distress and well-being.

As discussed in section 1.6 a strength of Yates et al.’s model (1999) was its ability to explore different mediators. As a result psychological inflexibility and valued living could be explored within the model. As a criticism of the model was the lack of theoretical basis for the chosen mediators, the current study lends some support to the continued investigation of psychological inflexibility and valued living. The results may also suggest that values and psychological inflexibility could link in to various sections of the model. That if individuals are high in valued living it may be as a result of being able to incorporate their values, in conjunction with psychological flexibility into the caring role, so they may not appraise themselves to be as burdened/overloaded by the hours of care they provide. It could also link into mastery as those high in psychological inflexibility may struggle to view the positive aspects of the caring role, such as mastery over a task, and incorporate other aspects into their value system, thereby impacting on their well-being.

Hobfoll’s conservation of resources model (1989) appears to fit reasonably well with the value component of ACT, which was assessed in the current study. Within Hobfoll’s model, resources are discussed as motivators which an individual strives to gain or conserve. As such they could link in with ACT’s values components whereby individuals aim to live in line with their values and as such experience stress when they are no longer able to do so. A key difference is that Hobfoll’s resources appear to be more transactional, as in an individual can gain or lose a resource and more tangible resources are included i.e. higher SES, car ownership. Whereas in ACT values are not achievable per se, rather they are areas that an individual deems important to live their life by, though there would likely be shorter term goals related to them. However, it does translate that when an individual’s value system is under threat either by internal or external events then distress may be
experienced. The results of the current study support this as valued living was related to well-being and distress and valued living moderated the relationship between distress and well-being. If resources are hypothesised as being similar to values then it can help explain why some carers have increased distress in some situations but not others, as it is dependent on each individual’s value system, some of which will be more readily incorporated into the caring role. With regard to Hobfoll’s model this provides additional support that when an individual’s important values/resources are under threat then distress may be experienced. For carers this could mean that if their resources are not able to be invested into their value system through the caring role then distress is experienced. This would also likely require psychological flexibility as it may be that an individual may not be able to continue to live in line with their values in the way they did previously, but have to examine different ways that they may still pursue their values. Part of this may include having to do this in the face of distress from the caring role. Some of which may be as a result of not being able to pursue the values in the way they once did.

The results of the study may also add understanding to Hobfoll’s model (2001) through psychological inflexibility. The model suggests that individuals will continue to attempt to restore their resources when these are under threat. If this attempt is successful then stress is reduced. However, if it is unsuccessful the individual may continue to strive to protect their resources which have the side-effect of using up other resources and potentially leading to resource depletion, thereby keeping the individual stressed. This is similar to the paradoxical affect of psychological inflexibility that repeated attempts to change, control or avoid the negative event leads to the individual becoming stuck with the negative event/emotion. As such for carers being able to incorporate their values into the caring role and recognise the difficult parts (resource depletions) while also being open to the positive parts (where values can be met) may be beneficial for their well-being.

This is in line with Folkman’s (1997) revision of Lazarus and Folkman’s (1984) model whereby carers continued to experience positive affect even in presence of
negative affect when they were able to find meaning within the role. This links with carers able to work their value system into the role, through finding aspects of the role that continue to allow them to live in line with their values.

The results of the current study are supportive of existing literature on mindfulness, psychological inflexibility and valued living, particularly that mindfulness and valued living are negatively correlated with distress and positively correlated with well-being. In addition, psychological inflexibility is positively correlated with distress and negatively correlated with well-being. It is relevant that this link is also shown in the current sample of carers, as less research into these areas and carers has been completed to date.

The results of the moderation analysis also provide more information on the nature of how psychological inflexibility and valued living may relate to the relationship between distress and well-being and burden and well-being. For the three analyses the direction of the relationship was unexpected as it suggests that psychological inflexibility strengthens the relationship between distress and well-being. This result would not be in line with the research and theory behind psychological inflexibility. However the moderation analysis is specific that this moderation relationship only occurs at low levels of psychological inflexibility, where it might be expected that individuals had more psychological flexibility. However, this assumes that using the AAQ-II as a measure allows for psychological inflexibility to be manipulated in this way. While historically the measure has at times been used in this way (Hayes et al., 2004) there is no psychometric data to support the use of the measure interchangeably between measuring psychological inflexibility and psychological flexibility (Bond et al., 2011). Therefore the result that the relationship between distress and well-being is strengthened when psychological inflexibility is low may not be as problematic as it is still measuring a level of inflexibility. As discussed in section 4.1 there were other problems with the current sample which may give rise to erroneous results which will be discussed more fully in Section 4.4.
Again valued living showed a negative moderation in the relationship between distress and well-being and burden and well-being, suggesting it too strengthened the relationships. Examination of the simple slope however shows that at high levels of valued living, well-being was still higher than when at mean level of valued living. This may indicate that there is a slight protective factor of high valued living, even if the relationship is still negative.

Valued living is linked to behavioural principles such as behavioural activation which is common in CBT, so it is perhaps not surprising that it is linked with well-being and distress. The key part of valued living is that it involves aspects of life which are important to the individual; therefore it is not just the behavioural activation that is important but the meaning of that behaviour for the individual and how it may impact on their values.

Clinically this is relevant as when working with carers who are distressed it may indicate that time needs to be spent on indentifying what values are important to them and whether they are still managing to complete these. This has wider implications as it may be important to ensure support is given to ensure the carer can continue to complete activities which are in line with their overarching values, this may mean providing individualised assessments regarding someone’s support needs e.g. respite and ensuring this provision is adequate. While previous research has indicated limited value to respite (McNally et al., 1999; Victor, 2009) it could be that this is due to respite alone not being enough. That the carer would benefit from additional support to identify important values that they are struggling to incorporate into their life and a way of being able to live towards them. There is perhaps some evidence for this as a positive long term impact was found when respite included a intervention on carer activities outside the caring role (Hichcliffe et al., 1995). The results with the valued living variable are clinically relevant as less work has been done in this area to show how valued living may relate to well-being and distress.
The current study provides some evidence that distress and well-being are not opposite ends of the same construct. Certainly there was a negative correlation found between distress and well-being, though large it was not a perfect correlation, and distress and well-being correlated with different variables suggesting they are different constructs. This is similar to Chappel and Reid’s findings (2002). If they were part of the same construct it would be expected that they would correlate with the same variables albeit in a different direction. The current study found no evidence for this.

The results of this study are suggestive of a need to examine mindfulness, psychological inflexibility and valued living in carers further, however they are not without their limitations. These will now be discussed.

**4.4 Strengths and Limitations**

A strength of the current study is that it looks beyond previous studies on carers which focused on discovering the stressors which impacted on carer distress and well-being. Instead it examines factors that may improve carers’ well-being, despite these stressors still being present. This is relevant as often there is little that can be done to change the stressors themselves beyond a temporary break through respite. As discussed in chapter one, the evidence for respite interventions is weak and effects are not maintained once the respite ends, making it a short-term intervention (McNally *et al.*, 1999; Mason *et al.*, 2007). The current study aimed to investigate factors that may be relevant to carer distress and well-being which may in the future be supportive of a carer intervention focusing on psychological inflexibility, mindfulness and valued living. As the current study found that there are relationships between these factors and carer distress, burden and well-being then it may indicate that interventions focused on increasing or reducing in the case of psychological inflexibility, may be potentially beneficial to the carer population.
While the current study is not an intervention the results remain clinically significant as they may prove useful to direct future interventions as it has been indicated that these relationships exist. This is important as a criticism of existing carer interventions is often there has been no research undertaken to indicate how or why they may be effective for carers (Parker et al., 2010). For example respite interventions are often used even though the evidence base for them is weak and studies examining respite have indicated it does not impact on carer distress or well-being. Whereas the current study indicates that mindfulness, valued living and psychological flexibility do have a relationship with carer distress, burden and well-being.

The study also aimed to sample carers from a variety of caring backgrounds as previous studies have been mainly aimed at carers who are caring for an older adult or an individual with dementia. The aim of this was to widen knowledge about carers as a group. Particularly due to the way research has been run in the past could lead to non-dementia carers being a neglected group with a limited understanding of their experiences. Obviously there are limitations of the research not being carried out in a specific group, such as generalisability. Particularly as the study did not recruit enough participants to allow comparisons between carer groups to be made, which had originally been one of the study’s aims. In addition the majority of carers came from the dementia carer population. This was mainly due to recruitment difficulties. Initially when attempting to recruit a mixed group of carers the majority of the sample were carers of someone with dementia. Therefore when recruitment became difficult, in order to increase the sample size, recruitment was focused on the higher proportion of carers who were already recruited (dementia carers). Particularly as this group seemed the most likely to participate. In addition it may have allowed some comparison between dementia carers and non-dementia carers to be made, if the sample size had been large enough.
Another limitation with the sample is that there is a bias towards female carers and male care-recipients. Again this raises the issue of the generalisability of the results found, however it is likely that this bias accurately reflects the caring population with females more likely to take on a caring role. What is less clear is why there is a gender bias with the care-recipients found in this sample as females would be as likely to require care as males.

An issue with the majority of the sample caring for someone with dementia may be that the results are more reflective of dementia carers than carers as a whole. This could create difficulties in generalising the results onto other caring groups. It may also suggest there is something different about the dementia carers who were sampled when compared to the other caring groups as more dementia carers came forward to participate. This could have been for a number of reasons such as they were less distressed, therefore more able to participate or conversely that they were more distressed so keen to participate to share their experiences in the hope that more support may be offered in the future or that they were more interested in participating in research. However, this could also be a reflection of how services are set up locally. Certainly it was easier to identify dementia carer support groups and professionals seemed more aware of these over other carer support group’s e.g. mental health, cancer, physical conditions.

The current study does provide an example of inclusive research into carers and in future studies it may be beneficial to consider this so all carer groups are considered in recruitment, even if they are split in part of the analysis to allow similarities/differences between groups to be considered. This would be clinically relevant as it would ensure that any models of care-giving or interventions which are developed are not just specific to dementia caregivers (the population which tends to be studied) therefore perhaps not representing non-dementia caregivers. Rather they may focus on the similarities with the care-giving role as a whole, which modifications could then be applied to the intervention/model depending on the care-
giving group. For example some models focus on level of cognitive impairment as a predictive factor for distress yet this would only be relevant for dementia carers and perhaps those caring for someone with a neurological condition. Yet these models are labelled generally as applying to carers, when their population has been dementia specific.

The study did not obtain the required minimum sample size of 66 (see section 2.7.1 for calculation) and analysis indicated power to be 0.70, based on a medium effect size. Therefore, it is of interest that significant results were found as there is an increased risk that significant results will not be found when a study is underpowered (Type II error). This is indicative of large effect sizes and examination of Pearson’s r in the significant results of the moderated multiple regression did suggest large effect sizes. It has been suggested that in addition to a risk of Type II errors, underpowered studies also risk inflated α and therefore Type I error and over-estimation of effect sizes. (Christley, 2010; Caze & Duffell, 2011). However, this tends to apply to studies with significantly lower power than what the current study obtained and where it is secondary not primary results which have been found significant. The current study’s finding that psychological flexibility moderates the relationship between distress and well-being was highly significant (p=.008) so is less likely to be affected by a Type I error. The other significant results were significant at the 0.05 level, however as the findings were based on a primary hypothesis and the study was close to approaching power at the 0.8 level it is likely they are true significant results. However, there is an issue that the obtained sample size is deemed inadequate for a multiple regression analysis so results need interpreting with caution as they may not be generalisable beyond the current sample.

It may have been helpful to have sampled the forms of support that carers had access to e.g. voluntary organisations, psychology services. This may have allowed an examination of whether there was an unmet need for carers. For example, if carers were reporting high levels of depression/anxiety but gaining access to the appropriate
services, then there may not be an unmet need in terms of protecting carers’ health. However, if carers’ responses indicated that they were highly distressed and lacking appropriate support then this would have highlighted an unmet need, which would be clinically relevant.

Another limitation of the study design is that carers were not asked if they had participated in any mindfulness based interventions. This would be important to measure as the results indicate that the group sampled do have naturally varying levels of mindfulness which would support the trait view of mindfulness (Brown & Ryan, 2003). This is that mindfulness is an innate ability that individuals may have present to a lesser or greater extent. However, that it can be increased through mindfulness practice and training. As the current study did not measure this it could be hypothesised that those who had higher levels of mindfulness did so as they may be practicing mindfulness thus had increased levels of mindfulness.

4.5 Recommendations for Future Research

Due to the current study sampling carers from mixed caring backgrounds it may be useful to replicate the study with a focus on one carer group. This would allow comparisons between carer groups to be made and allow an exploration of similarities and differences. Particularly as other research has indicated differences between carer groups, for example dementia and non-dementia carers (Pinquart & Sörensen, 2003). Given the relative ease of recruiting dementia carers to the study this may be the most appropriate group to commence further research with.

The current study provided evidence that significant relationships exist between carer distress and mindfulness, psychological inflexibility and valued living. Equally these significant relationships existed with carer burden and well-being. In addition there was evidence of psychological inflexibility moderating the relationship between distress and well-being and valued living moderating the relationships between both distress and well-being and burden and well-being. These results indicate a need to
examine these relationships further. Therefore it may be interesting to explore these relationships in an intervention study to assess whether focusing on increasing carers’ mindfulness, psychological flexibility and valued living could positively impact on carer well-being and distress and/or carer well-being and burden. Based on the current study’s results it is proposed that an ACT intervention may be suited due to ACT focusing on all three variables measured in the current study. It is proposed that the intervention may focus on carer values and the exploration/re- engagement of these. This will use processes from ACT such as psychological flexibility and mindfulness. It is noted that a carer intervention framework currently exists (Márquez-González et al., 2010). This framework aims to intervene mainly through ACT values work whereby the carer focuses on their values and is supported to explore and re-engage with these, likely using the caring role as a tool in which to do so, as well as widening their perspective to look at their value system outside that role. Similar to Folkman (1997), giving meaning to the ordinary is a target for the intervention. Through doing this an aim would be to allow the carer to widen their focus to notice positive aspects of the role that they may have neglected or over-looked due to a focus on the negative as a result of increased psychological inflexibility. This would hopefully increase their engagement and pursuit of their values, leading to greater well-being and reduced feelings of burden and overload. In order to do this value work, the other processes of ACT would also be used, such as psychological flexibility and mindfulness. The results of the current study provide support for this framework with the focus on values as values was found to moderate relationships between distress and well-being and burden and well-being in carers.

Due to previous criticisms of research in ACT and mindfulness (see chapters 1.9.3 and 1.11.2) it is important for new research not to perpetuate these criticisms. Therefore it is recommended that fully trained therapists should be used to deliver the intervention using previously researched and standardised protocols. This is to ensure that if non-significant results are found this is not due to deviation from accepted ACT interventions, as has been the possible case in previous research. In addition pre-post-measures of the proposed mechanism of change should be carried
out to provide evidence that it is increased mindfulness, psychological flexibility and/or valued living that his having the impact, if present, on distress, well-being and burden. The inclusion/exclusion criteria for carers should also be carefully considered as to who will be classified as a carer and whether the intervention would be open to a mixed group of carers or a single group e.g. dementia caregivers.

Prior to an intervention study commencing it would be advantageous to explore the role cognitive fusion may have in terms of carer burden and well-being. The current study did not include this component of ACT however it should be considered in future research of this type. Cognitive fusion refers to an individual being entwined with their thoughts to the extent that they view them as truths about a situation or feeling (Hayes et al., 2003). This is linked to the concept of psychological inflexibility as it is considered those high on psychological inflexibility would also demonstrate high cognitive fusion. Therefore, a goal would be cognitive defusion, the recognition that thoughts are just thoughts and not statements of truth about actual or imagined events. This then allows an individual to engage in different behaviours that once seemed impossible. Returning to the example of the socially anxious individual, in addition to anxious feelings they are likely to have anxious thoughts or images such as imagining that if they go out for lunch that they will lose control and panic. If they are fused with their thoughts they will rate the likelihood of this occurring as high, which likely reinforces their avoidance behaviour. However, cognitive defusion allows the acceptance of the image/thought as solely a mental event, not fact or a prediction of the future, therefore changing how thoughts can impact on an individual behaviourally and emotionally. This may link to carers experiences whereby they imagine the likelihood of an unpleasant even occurring when they are caring for someone as high, and may spend a great deal of time ruminating on this or attempting to avoid. It may also lead carers to catastrophise about parts of their situation, which they then may inadvertently reinforce as they are primed to look for the negative parts, making focusing on positive aspects such as how the role can link into their values difficult.
A questionnaire assessing cognitive fusion has been developed (Gillanders et al., in press) and inclusion of this into a future study, similar to the original, will allow investigation of whether cognitive fusion also impacts on carers well-being and distress and to what extent. This would also enable a comparison between mindfulness, psychological inflexibility, valued living and cognitive fusion, in relation to carers, to be made to see if one or more of these components are better able to explain the relationships between distress and well-being and burden and well-being or if it is all the components together which proves critical. This could then have implications for future research into carer interventions.

4.6 Summary
The current study, although not all the hypotheses are fully supported, gives an indication that it may be important to study mindfulness, psychological flexibility and valued living in carers further in order to identify potentially efficacious interventions. The findings suggest that mindfulness, psychological inflexibility and valued living are associated with distress, well-being and burden; therefore interventions focused on changing these factors may impact positively on carer outcomes. The next step to this study would be to conduct an intervention study examining mindfulness or ACT in a carer population.

4.7 Conclusion
In conclusion two of the study’s hypotheses were supported and two were partially supported. The results of the study indicate that psychological inflexibility is related to increased distress and burden and reduced well-being; mindfulness and valued living are related to increased well-being and decreased distress and burden. There was evidence of psychological inflexibility moderating the relationship between distress, and valued living moderated both the relationship between distress and well-being and the relationship between burden and well-being.


Gillanders, D.T., Bolderston, H., Bond, F.W., Dempster, M., Flaxman, P.E., Campbell, L., Kerr, S., Tansey, L., Noel, P., Ferenbach, C., Masley, S., Roach, L.,


Öst, L.G. (2009). Inventing the wheel once more or learning from the history of psychotherapy research methodology: reply to Gaudiano's comments on Öst's (2008) review. *Behavior Research and Therapy, 47*(12), 1071-1073.


Appendix I

Communication with NHS Ethics Department

(from e-mail communication, identifying details removed)
RE: Ethics Query

Sent: 13 October 2010 13:06
To:  

Dear [Name],

Thank you for your email.

After review of your protocol I do think that your project is a research project and would need to undergo Ethical Review. However, as you recruiting through the [Institution] and not through the NHS then it does not come under the remit of the NHS NRES Committees. Therefore you would not need to apply to the NRES Committees.

Please note the advice given is based on the information supplied. If any information is withheld or changed at a later date this may affect the advice given.

Good luck with your project.

Best wishes,
Appendix II

Letter of NHS Ethical Approval

(all identifying details Removed)
04 October 2012

Dear [Name],

Study title: Investigation of factors which may mediate the relationship between distress and well-being in unpaid carers.

REC reference: [Redacted]

Thank you for your letter of 3 October 2012, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/MSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.
Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved by the Committee are:

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<td>Investigator CV</td>
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<td>Letter of invitation to participant</td>
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Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.
After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NS/0113 Please quote this number on all correspondence

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

Yours sincerely

[Signature]

Professor
Chair

Enclosures: “After ethical review – guidance for researchers” [SL-AR2]

Copy to: NHS R&D Department
Appendix III

Letter of approval from NHS Research and Design Committee

(all identifiable details removed)
Management Permission for Non-Commercial Research

NOSRES Ref: [redacted]
Project title: Investigation of factors which may mediate the relationship between distress and well-being in unpaid carers

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS [redacted] & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the Research Governance Framework for Health and Community Care (2006, 2nd edition), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

It is particularly important that you inform us when the study terminates.

The R&D Office must be notified immediately and any relevant documents forwarded to us if any of the following occur:

- A change of Principal Investigator, Chief Investigator or any additional research personnel
- Premature project termination
- Any amendments – substantial or non-substantial (particularly a study extension)
- Any change to funding or any additional funding

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

Yours sincerely

[Signature]

Non-Commercial Manager

Cc Dr. [Redacted] Quality Assurance Manager, NHS [Redacted]
Appendix IV

Patient Information Sheet
Factors Influencing Wellbeing in Carers

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The purpose of the current study is to look at protective factors in carers. For the purpose of this study the term carer is used to identify a person who provides care for another individual and does not receive payment for this, unless they are entitled to carers allowance.

We understand that caring for an individual with a long term health condition can be stressful and we are interested in finding out the types of things that carers do to cope with this. We are also interested in whether how people think about their situation has an impact on the stress that they experience and how they cope. We hope by investigating this that it will help us work better in being able to support carers and the people they care for.

Why have I been chosen?

You are being asked to consider taking part in the study as you have been identified as a carer either through your attendance at a carers group or an appointment at the xxxxx or xxxxxx departments.
Do I have to take part?

No. It is up to you to decide whether to take part and participation is entirely voluntary. Choosing not to take part or withdrawing from the study will not affect your or the person(s) you are caring for current/future treatment in anyway. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. If you require more information to help you decide whether or not you wish to take part, please contact the researcher on the details below.

Consent to participate in the study will be implied if you return a completed questionnaire pack to the researcher.

If you decide to take part please note down the participant number which appears at the top of every questionnaire. This will be used to identify your responses should you wish to withdraw from the study.

What will happen to me if I take part?

If you do wish to take part we ask that you complete the questionnaire pack enclosed and return it to us using the stamped addressed envelope provided. You do not have to share your questionnaire responses with anyone else.

What will be done with the information I give?

Any information that you provide will be treated with the strictest confidence. All information will be anonymised and will be held in a secure office in a locked filing cabinet. Your name will not be used on any of the information you provide and instead you will have a research code number to ensure confidentiality.
What are the possible disadvantages and risks of taking part?

The disadvantages and risks of taking part are minimal. It is possible that some of the questions in the questionnaires may identify areas of difficulty or feelings that you had not considered before. If you require support with this you can speak to your GP. If, from scoring your questionnaires the researcher thinks it may be beneficial for you to speak to your GP a confidential letter will be sent to your G.P from the address you provided on the demographic information. If you do not provide their address the researcher will be unable to contact them. If you do provided an address the researcher will only use your address for this purpose and it will be destroyed once your questionnaires have been scored.

What are the possible benefits of taking part?

The information from this research project will increase our understanding of factors that can influence how people cope with caring for a person. It is hoped that this might enable us to provide better support to carers and the people they care for.

What will happen to the results of the research study?

The anonymised results of this research study will be written up for the researcher’s thesis which will be marked by the University of Edinburgh. It is likely that it will also be written up as a scientific journal article in order to contribute to current research within the field. The research results will also be disseminated through presentations to interested parties. No participants will be indentified in any report or presentation.

Who has reviewed the study?

The study has been reviewed by the Clinical Psychology Ethics Review Panel and the xxxxxx Research Ethics Committee.
Contact for Further Information

Dr. x
Trainee Clinical Consultant
Psychologist

Contact Independent of the Study Team

Dr. X
Clinical Psychologist

If you wish to make a complaint about the study please contact:

Feedback Service
NHS X

Thank you for considering participating in this study and taking the time to read this information sheet.
Appendix V

Demographic Questionnaire
I would like to start by asking some questions about you and the person that you care for. Please note, this information will be held in the strictest confidence and all responses will be anonymised. If you currently care for more than one person please tick here □ and if possible answer the following questions for all the people you care for.

Demographic Information

How old are you?

What is your gender? Male/Female

How would you describe your employment status?

- Employed full-time
- Employed part-time
- Unemployed
- Retired
- Self-employed

Other (please specify):

What is your relationship to the person you care for?

What is the diagnosis of the person you care for? (please include all diagnoses)

If the person you care for does not have a diagnosis, please specify why you care for them e.g. frailty
Do you live with the person you care for?  
Yes/No

Other (please specify):

How old is the person you care for?

What is the gender of the person you care for?  
Male/Female

How long have you been caring for this person? (please circle)
Less than 6 months  6 months – 1 year  1-2 years  3-4 years  5-10 years  10-20 years  20+ years

Approximately how many hours per week do you spend caring for this person? (please circle)
0-5  6-11  12-17  18-23  24-29  30-35  36-41  42-50  50-100  100+

Do you currently receive Carers Allowance?  
Yes/No
The following boxes are related to the type of care that you provide to the person that you care for, please tick all that have to you applied within the last month.

- Transport e.g. to appointments
- Social support e.g. visiting regularly, going on outings
- Personal care e.g. washing, dressing, toileting
- Shopping e.g. groceries
- Household tasks e.g. cleaning, cooking, gardening
- Medical Care e.g. giving medicines
- Financial e.g. paying bills, collecting benefits, managing finances
- Other – if possible please specify below

Overall how stressful do you find your caring role?

1 2 3 4 5
Not stressful Mildly Moderately Highly Extremely
at all stressful stressful stressful stressful

We ask that you complete your and your G.Ps name and address in case we need to contact them regarding any of your questionnaire responses. If you choose not to complete the address details below we will have no way of contacting you. This information will be held confidentially and will be destroyed once your questionnaire responses have been scored.