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Effectiveness of mindfulness meditation-based interventions on anxiety in older adults: A systematic review

and

An investigation of the relationship between carer burden and depression and anxiety in older kinship carers

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Contents

Research Portfolio Abstract

Objective: This thesis had two objectives. The first was to examine the effectiveness of mindfulness-meditation interventions on anxiety in older adults. This was addressed through undertaking a systematic review, providing a comprehensive and up-to-date critique of the literature. The second objective was to explore the relationships between carer burden and depression and anxiety in older kinship carers. The empirical study also aimed to use conditional process analysis to explore how the psychological resources of self-compassion, dispositional mindfulness and mastery affect the relationship between carer burden and psychological wellbeing.

Method: In relation to the first research objective, a search strategy was devised and eight electronic databases were searched to identify potential articles. Studies were screened according to specific inclusion and exclusion criteria, with the included reviews undergoing a narrative synthesis, quality assessment and RE-AIM analysis. An independent reviewer was utilised to conduct a quality assessment and RE-AIM analysis on half of the included studies. In relation to the second research objective, a cross-sectional online study was conducted with kinship carers over the age of 55. Participants completed five quantitative self-report questionnaires measuring carer burden, anxiety, depression, self-compassion, mindfulness and mastery.

Results: In the systematic review, 11 studies met eligibility criteria and were included in the narrative synthesis, quality appraisal and RE-AIM analysis. Reduction in levels of anxiety were found to be significant in seven of the studies, showing potential benefits in a variety of older adult populations. However, there were a number of studies demonstrating mixed or non-significant results. The RE-AIM analysis highlighted that clinical implementation of mindfulness meditation interventions was often not well considered.
In the empirical study, 113 kinship carers completed the study. Results indicated that carer burden was positively associated with depression and anxiety. Dispositional mindfulness and mastery were found to mediate the relationship between carer burden and depression. In the relationship between carer burden and anxiety, dispositional mindfulness was found to be a mediator, whilst self-compassion was found to moderate the relationship.

Conclusions: The findings of the systematic review are promising for the effectiveness of mindfulness meditation interventions on anxiety in the older adult population. Further research is needed to clarify the strength of effects, by ensuring studies follow strict protocols to ensure consistency and allow replication. The findings of the empirical study provide evidence that self-

compassion, dispositional mindfulness and mastery serve as potential protective factors between levels of carer burden and psychological wellbeing, in older kinship carers. This has important clinical implications in terms of the treatment of psychological difficulties in this population, as well as highlighting the role of preventative interventions. Additional research is required to better understand the interactions between these variables in older kinship carers.

Lay Summary

This thesis consists of two chapters that explore emotional wellbeing in older adults, an age group in which mental health issues are often underreported. The first chapter contains a review of research studies to help understand if mindfulness meditation therapy improves levels of anxiety in adults over 65 years old. Mindfulness meditation therapy teaches people the skills to become more aware of the present moment and take a non-judgmental stance towards their thoughts and feelings. This review analysed the results of eleven studies that explored the effects of mindfulness meditation on levels of anxiety in a range of different older adult populations. In summary, encouraging results were found, with many of the studies finding that those who took part in mindfulness meditation therapy had reduced anxiety at the end of their treatment. However, not all studies found the same benefits of mindfulness meditation on anxiety, leaving it difficult to draw firm conclusions. The review also found that the included studies did not always consider how mindfulness meditation therapy could be run outside of the research setting, making it harder to transfer the results to community and medical settings.

The second chapter of this thesis presents a research study, the aim of which was to investigate the mental wellbeing of kinship carers over 55 years of age. A kinship carer is someone who is looking after a child of a relative or friend on a full-time basis. 113 kinship carers took part in the study by completing a series of online questionnaires, measuring a number of psychological factors. The study found that kinship carers who were experiencing higher levels of carer burden were more likely to report increased levels of anxiety and depression. The study also found that mindfulness, self-compassion and mastery (i.e., someone's belief that they are in control of their life circumstances) may act as protective factors against depression and anxiety. These are important findings for older kinship carers as it highlights the potential need for mindfulness- and compassion-based psychological therapies to be offered, both to prevent and treat anxiety and depression in this population.

Chapter 1: Systematic Literature Review

Effectiveness of mindfulness meditation-based interventions on anxiety in older adults: A systematic review

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Abstract

Objective: This review sought to provide a comprehensive analysis of the available literature surrounding the effectiveness of mindfulness meditation interventions on anxiety in adults of 60 years and older. It also aimed to conduct a RE-AIM (Reach, Efficacy, Adoption, Implementation and Maintenance) analysis to provide critique regarding how transferable the results are to a non-research setting.

Method: Systematic searches were conducted using eight databases to identify appropriate studies. These were methodologically appraised and the RE-AIM analysis applied with input from an independent researcher to reduce bias.

Results: A total of eleven studies met criteria for inclusion (seven RCTs, one non-randomised controlled study, three pre-post studies). Reduction in levels of anxiety were found to be significant in seven of the studies, however results across studies were mixed. These findings were across a range of clinical and non-clinical settings. The overall methodological quality was moderate to good, but clinical implementation was often not well considered. Additional findings included decrease in depression, caregivers' stress and increased sleep.

Conclusion: Findings are promising for the effectiveness of mindfulness meditation interventions on anxiety in the older adult population. Further research is needed to clarify the strength of effects, by ensuring studies follow strict protocols to ensure consistency and allow replication.

Keywords: Mindfulness, meditation, intervention, systematic review, anxiety, older adults

Highlights

- There are a limited number of studies concerning the effectiveness of mindfulness meditation interventions in older adults.
- This review found promising evidence for the effectiveness of mindfulness meditation interventions in reducing anxiety in older adults.
- Significant effects were seen across clinical and non-clinical settings and with a range of population groups, including caregivers, medical inpatients and those taking mindfulness courses.
- The RE-AIM analysis found studies were generally good at reporting on the reach and efficacy dimensions but were lacking in relation to the adoption, implementation and maintenance dimensions.

1. Introduction

1.1. Older Adult Mental Health

Increases in longevity, coupled with an ageing population mean that older adults are the fastest growing section of the world's population (World Health Organisation, 2021). The World Health Organisation defines an older adult as an individual aged 60 and over, stating that by 2050 older adults will form approximately 22% of the overall population. This heterogeneous population encounter multiple changes in their biological, cognitive, psychological and social health which increase their vulnerability to developing psychological problems (Aldwin, Yancura, & Lee, 2021), and this is before consideration of the impacts of the COVID-19 pandemic. However, despite the increased susceptibility, empirical evidence reports inconsistent findings. Whilst some studies report a lower prevalence of mental health difficulties in advanced age (Steptoe, Deaton, & Stone, 2015) others estimate that as many as one in four older adults are currently experiencing a mental health disorder, with anxiety disorders reported as the most prevalent of these (Andreas et al., 2017). Furthermore, the prevalence of anxiety symptoms in older adults in the community ranges from 15% to 52.3%, with prevalence significantly higher in females (Bryant, Jackson, & Ames, 2008). There are a number of well detailed explanations used to explain the heterogeneity of findings. These include increased coping strategies (Yang, 2007), poor mental health literacy (Beaunoyer, Landreville, & Carmichael, 2019) and increased stigma surrounding psychological difficulties (Forbes, Crome, Sunderland, & Wuthrich, 2017).

Another key issue relates to the assessment of anxiety in this population with differences in symptom presentation compared to younger adults (Wuthrich, Johnco, & Wetherell, 2015) and high comorbidity with other mental and physical health disorders complicating matters (Kogan, Edelstein, & McKee, 2000). For this reason, when using self-report measures to assess anxiety it is recommended that the use of psychometric measures specifically developed for this population be utilised, however these are scarce in number and do not always have sufficient psychometric properties (Balsamo, Cataldi, Carlucci, & Fairfield, 2018). These measures include the Geriatric Anxiety Scale (GAS), the Geriatric Anxiety Inventory and the Adult Manifest Anxiety Scale- elderly version (AMAS-E) and tend to avoid questions regarding somatic symptoms, as these items may yield inflated scores in older adults. Alternatively, researchers may employ existing anxiety measures which have been psychometrically tested in the older adult population such as Penn State Worry Questionnaire (PSWQ), Beck Anxiety Inventory (BAI), the Depression Anxiety Stress Scale (DASS; Gloster et al., 2008).

Furthermore, existing research concerning anxiety in the older adult population has shown differences in the focus of anxiety compared with younger adults. Whilst the content of worry for older adults is more likely to be allocentric, related to the health and welfare of loved ones, their own health or world events, younger generations' worry is more likely to be egocentric in nature (Gonçalves & Byrne, 2013). For this reason, it is important that treatment options are catered specifically for this population. Both psychological therapy and selective serotonin reuptake inhibitors (SSRIs) are recommended as the gold standard treatment of Generalised Anxiety Disorder (National Institute for Health and Care Excellence [NICE], 2011) in the UK. However, there are no specific guidelines for older adults. A meta-analysis on the interventions for GAD in older adults did find that both pharmacological and psychotherapeutic treatments were significantly more effective at reducing anxiety when compared to a control condition (Gonçalves & Byrne, 2012). Whilst this review is encouraging, SSRI side effects have been shown to worsen with age and their use in people aged 65 and over is associated with serious adverse effects and mortality (Coupland et al., 2011). Cognitive Behavioural Therapy (CBT) is recommended as the gold standard psychological treatment for anxiety disorders and has a substantial evidence base, including in older adults (Wuthrich et al., 2021). However, critics argue against the effectiveness of the cognitive change strategies at the heart of traditional CBT. This criticism prompted the development of a new generation of cognitive and behavioural therapies (Longmore & Worrell, 2007). These so called "third wave" psychological therapies have begun to build an evidence base in the treatment of psychological difficulties in older adults (Davison, Eppingstall, Runci, & O'Connor, 2017; Moghadam, Baharvandi, & Rashidi, 2020). Despite the research, access to individual psychological treatment requiring highly skilled practitioners is often problematic due to a lack of mental health professionals, especially in developing countries (World Health Organisation, 2021). Therefore, research into group-based psychological interventions that can be delivered by a wider range of individuals, in a variety of settings, is ever growing. Mindfulness Meditation Interventions (MMIs) are one such group, building an evidence base for treatment of a range of psychological difficulties (Zollars, Poirier, & Pailden, 2019).

1.2. Mindfulness Meditation Interventions (MMIs)

Mindfulness is the intentional and non-judgmental awareness of thoughts, feelings and sensations that occur in the present moment (Kabat-Zinn, 2009). The application of mindfulness focuses on cognitive and emotional regulation with the aim of helping individuals become more aware of their internal and external environment, whist encouraging openness, curiosity and acceptance. The term mindfulness meditation describes a subfamily of meditation techniques, originating from ancient

Buddhist practices. The learning and practice of mindfulness meditation is used to develop an individual's ability to be mindful. The basic premise underlying mindfulness meditation practice is that it counteracts the excessive focus on the past or future, often a key maintaining factor in anxiety and depression, by transferring the focus to the present moment non-judgementally and openly (Kabat-Zinn, 2003). Furthermore, it is believed that by teaching people to respond to stressful situations with reflection rather than reflexively, mindfulness-based interventions can oppose experiential avoidance strategies, a further maintaining factor in many, if not all emotional disorders (Maltais, Bouchard, & Saint-Aubin, 2019). With research suggesting that older adults may be more likely to use experiential avoidance than younger adults (Pierson, Roche, & Denburg, 2019) it could be suggested that mindfulness meditation interventions may be well suited for this population.

There are various interventions which apply mindfulness meditation at their heart, including Mindfulness Based Stress Reduction (MBSR; Kabat-Zinn, 2003), Mindfulness Based Cognitive Therapy (MBCT; Segal & Walsh, 2016), Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 2009), Dialectical Behavioural Therapy (DBT; Linehan, 2015) and Compassion Focused Therapy (CFT; Gilbert, 2005). Although these therapies contain similar mindfulness techniques, they differ with respect to their theoretical background. ACT is based on the relational frame theory, derived from functional contextualism and is centred around the behaviour and values of individuals (Boone, Mundy, Morrissey Stahl, & Genrich, 2015). DBT is grounded in dialectics, using a systemic approach based on biosocial theory and was originally developed for the treatment of Borderline Personality Disorder (Feigenbaum, 2007). CFT is rooted in an evolutionary, functional analysis of the social and emotional systems and uses a specific focus on self-compassion in its mindfulness meditation exercises. MBSR and MBCT were both developed from ancient Buddhist philosophy, integrated with modern psychological and medical practice and use mindfulness meditation as their main component (Chiesa & Malinowski, 2011). MBSR most closely resembles traditional Buddhist meditative practice and is focused on the learning and practice of mindfulness meditation techniques including body scan, mindfulness movement and sitting meditation (Kabat-Zinn, 2003). MBCT was developed as a method for the prevention of relapses of major depression and integrates CBT with mindfulness helping individuals understand links between their thoughts, feelings and behaviours (Segal, Williams, & Teasdale, 2018). MBSR and MBCT were both developed to be delivered to participants in eight structured sessions delivered over eight weeks, with a half day retreat incorporated between week seven and week eight. An element of home practice is also encouraged between sessions (Kabat-Zinn, 2003).

A common misconception amongst the general public is that mindfulness meditation is undertaken to achieve a sense of relaxation. Whilst there may be overlap in some of the exercises in mindfulness meditation and relaxation, for example breathing exercises, they are undertaken for different purposes. Whilst the goal of a relaxation exercise is to elicit a psychophysiological state of hypo arousal the aim of mindfulness meditation exercises are to focus one's attention on the present moment, including physical and psychological sensations. Many of the interventions described include both mindfulness meditation and relaxation interventions, both of which have been shown to be effective in reducing psychological distress (Corbett, Egan, & Pilch, 2019). However, it is important to consider the confounding influence relaxation exercises may have when examining the effectiveness of mindfulness meditation interventions in order to determine the mechanisms of change.

1.3. Effectiveness of MMIs

MMIs have been studied for the treatment of a range of mental health difficulties (Goldberg et al., 2018), physical health problems (Grossman, Niemann, Schmidt, & Walach, 2004) and improving well-being in non- clinical samples (Khoury, Sharma, Rush, & Fournier, 2015; Lomas, Medina, Ivtzan, Rupprecht, & Eiroa-Orosa, 2019). The results suggest MMIs are effective in treating anxiety, depression, chronic pain, decreasing stress and burnout, with moderate effect sizes. In relation to older adults there are far fewer studies and reviews. A systematic review on the effectiveness of MBCT for the treatment of anxiety and depression in older people found insufficient evidence (Thomas, Chur-Hansen, & Turner, 2020). This was due to substantial weaknesses in the methodological rigour of the studies included, however seven of the nine included studies reported improvements in depression. This review only included studies where participants had a diagnosis of depression and anxiety and did not employ an age criterion for the inclusion of studies. Li & Bressington (2019) conducted a review into the effects of MBSR on depression, anxiety and stress in older adults. Although they concluded that MBSR is more effective than a waitlist control group in reducing depression, they could not draw conclusions regarding MBSR's effect on anxiety or stress. This was partly due to the low number of studies included (n=6), as well as incorporating studies with participants younger than 60 years. Focusing on a more specific outcome, Reangsing et al. (2021) conducted a recent meta-analysis which examined the effectiveness of mindfulness meditation interventions on depression in older adults. The authors reported significantly improved depression (effect size= .65, 95% CI 0.35, 0.94) in participants undertaking MBSR, MBCT or adapted mindful meditation interventions compared to controls. This effect was greater in Asian populations compared to those from Europe and North America. This study included participants from a range of

settings and included both clinical and non-clinical samples, providing greater transferability of results. However, it could be argued that the inclusion of studies using MBCT does not solely explore the effectiveness of mindfulness meditation as MBCT involves the use of cognitive therapy, itself known to be effective in the treatment of depression. To date, there is no known review exploring the effectiveness MMIs on anxiety in older adults. Furthermore, none of these reviews considered how the results of the studies included can be carried into "real-life" clinical practice.

The challenges of translating research findings into practice are well documented (e.g. Rapport et al., 2018). The use of pragmatic frameworks to evaluate the implementation and outcome of interventions can help to bridge the gap between scientific knowledge and dissemination (Gaglio, Phillips, Heurtin-Roberts, Sanchez, & Glasgow, 2014). This is especially relevant in relation to psychological studies, where elements such as attrition and adherence rates, representativeness of the study population and the availability and cost of resources, are essential to consider alongside effectiveness to insure maximum impact.

In sum, MMIs have been shown to be effective for reducing a range of psychological symptoms in adults and improving symptoms of depression in older adults. Whilst various systematic reviews have looked at elements of MMIs, including a recent review specifically covering MBCT in older adults, these have their limitations. As discussed, it is likely that anxiety is under reported in this population, therefore there is merit in evaluating studies which use both clinical and non-clinical populations of older adults. Furthermore, none of these reviews evaluate the transferability of the interventions beyond the research setting.

1.4. Review Aims

This study has two objectives:

1) To examine the effectiveness of mindfulness meditation interventions on improving psychological symptoms of anxiety in older adults.

2) To apply the RE-AIM analysis to enhance the quality evaluation of found studies by reviewing how well the findings of the studies transfer beyond the research setting.

2. Method

The protocol for this systematic literature review was registered with PROSPERO (registration number: CRD42021250231) on the 20th April 2021.

2.1. Search Strategy

Searches were conducted on 18th November 2021 in the PsycINFO, MEDLINE, EMBASE, CINAHL Plus, PROQUEST Social Sciences, PROQUEST Dissertation and Theses Global, Scopus and Mindfulness-Journal Springer.

Additional sources such as Google Scholar, PROSPERO, and the Cochrane Database of Systematic Reviews were searched to ensure that the review question was original and had not already been completed, or was in the process of being completed.

Reference lists of relevant research papers and systematic reviews were also searched. The following search terms were used: “mindful* meditat*” OR “mindful* based stress reduction” OR “MBSR” “anxi*” AND “old* adult*” OR “aging” OR “ageing” OR “elder*” OR “geriatric*”.

2.2. Inclusion and Exclusion Criteria

Studies were included if they (a) contained an original research study, of both quantitative and mixed- method design, including RCTs, quasi-experimental designs, longitudinal follow-ups and case studies; (b) had undergone peer-review process, including doctoral theses as these undergo a process of quality control similar to that of a peer review; (c) evaluated mindful meditation- based interventions, including MBSR, mindfulness meditation or adapted mindfulness interventions with mindfulness meditation as the main intervention component, delivered both individually or in a group setting; (d) included anxiety as a quantitative outcome, measured pre and post intervention using a valid and reliable psychometric tool; (e) took place in any setting, including clinical, university populations, sheltered housing or within community; (f) included participants aged 60 years and over including oldest-old; (g) were written in English or had an available English translation.

Studies were excluded if (a) they were qualitative only; (b) participants had severe cognitive difficulties, including a diagnosis of a degenerative condition, self-reported memory problems or a learning disability; (c) the intervention group had a combined psychological modality that could confound results such as cognitive aspects, including MBCT, ACT, or DBT, as well as yoga and tai chi; (d) the paper was a conference abstract or book chapter or had not been peer reviewed.

After searching the databases, any duplicates were removed. Studies were then screened for relevance by title and abstract, with the eligibility of the remaining studies assessed against the inclusion/exclusion criteria during full text review.

2.3. Data Extraction

Data extracted from accepted studies included the location and design of the study; sample size and population; intervention type and setting; outcome measures; and results. Data extraction was repeated at multiple time points to minimise errors.

2.4. Quality Assessment

The methodological quality of the selected studies was assessed using the Joanna Briggs Critical Appraisal Tools (Johanna Briggs Institute, 2017).

In addition, this review applied the RE-AIM framework (Glasgow et al., 2019; Glasgow, Vogt, & Boles, 1999). This framework assesses the Reach, Efficacy, Adoption, Implementation and Maintenance of each study and can therefore give an indication of how transferable the results are out-with the research setting. Reach concerns the representativeness of samples by examining the extent to which studies are reaching their target population. The efficacy indicators seek to explore how well the study measures the intervention's effectiveness. Adoption assesses the researcher's reporting of how well the intervention was organised and delivered. The implementation indicators explore the consistency of the intervention delivery, whilst the maintenance criteria assess the extent to which the researchers report the continuation of the intervention following the study. Each study was rated to either meet the criteria or not on 21 indicators, falling under the five dimensions, as per the guidance (https://re-aim.org/#0).

The methodological quality of all studies was rated by the first author who also applied the RE-AIM analysis to all studies. An independent reviewer (third author) rated a subsample of six randomly selected papers (63.6%) and analysed all the studies applying the RE-AIM framework. Initial inter-rater agreement between authors was 82.3%. All differences were discussed and amended to achieve full agreement with 94.3% of the first author's ratings retained.

2.5. Data Synthesis

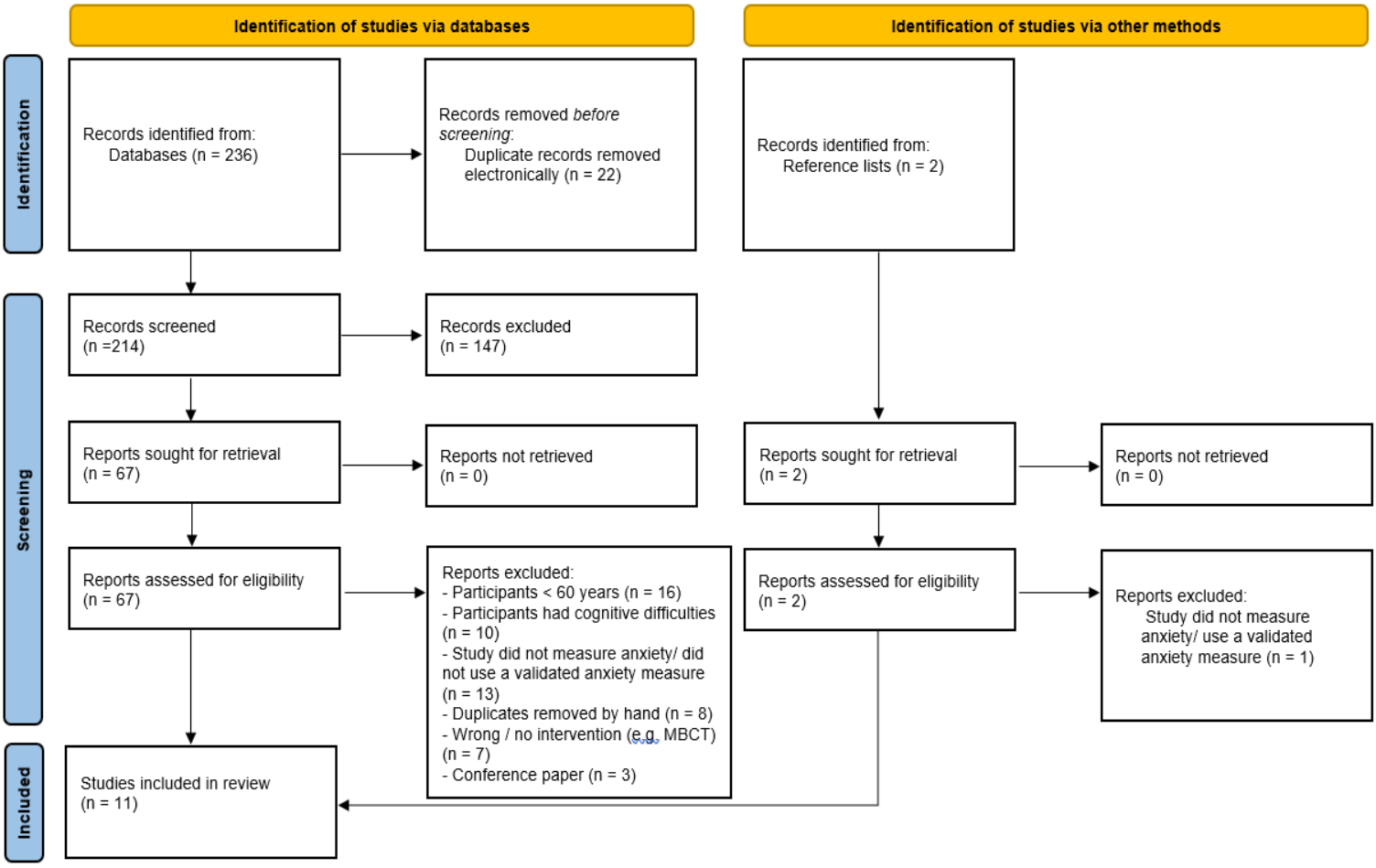
The heterogeneity of anxiety measures used as well as the differing population groups within the studies prevented a meta-analysis from being carried out, therefore, a narrative synthesis of the included studies was performed. This was conducted in accordance with the RE-AIM framework, which was deemed the most appropriate to use due to its focus on highlighting the potential public health impact of behavioural interventions (Glasgow, Vogt, & Boles, 1999).

3. Results

3.1. Search Results

A total of 236 studies were found through searching the databases. See Figure 1 for PRISMA Flow diagram of review process. Two further studies were identified from searches of relevant reviews and reference lists. Duplicates were removed and titles and abstracts were screened for relevancy. After this step, 68 studies remained. 57 articles were excluded for not meeting inclusion criteria. The remaining 11 studies were included in this review.

Figure 1. PRISMA Flow Diagram of Review Process (Page et at., 2021)



3.2. Study Designs and Interventions

The characteristics of the 11 selected studies are summarised in Table 1. Of the 11 studies included in the review, seven were randomised controlled trails, one non-randomised controlled study and three non-randomised experimental studies. Only one study used a mixed methods design (Moss et

al., 2015). Of the eight studies which had a control condition, four of these were waitlist control groups or treatment as usual. Other control groups included physical leisure activities (Ahmadpanah et al., 2017; Thilakan et al., 2020) and psychoeducation surrounding aging, stress and mood coupled with daily memory strategies (Smart & Segalowiz, 2017). Whilst all studies measured anxiety pre- and post- intervention, only one study followed up outcomes at four weeks after the intervention (Ahmadpanah et al., 2017).

The most common intervention used in the studies was an adapted Mindfulness Based Intervention (MBI) with seven of the studies using this. MBIs included a mixture of mindfulness techniques and attention training and were different in each of the seven studies. Two of these studies (Vela, 2006; Thilakan et al., 2020) stated they used relaxation techniques as part of their intervention, a potential confounding factor when considering the results of the studies. Three of these seven MBI studies cited Kabat- Zinn (1990) as the basis of their intervention; however, they did not follow the set protocol. Four of the studies used Mindfulness Based Stress Reduction Therapy (MBSR; Kabat-Zinn & Hanh, 2009), following Kabat-Zinn's protocol with greater fidelity, however all four studies made adaptations to the protocol to fit their population groups. These adaptations included delivering the intervention on an individual basis over a 10-day period as opposed to weekly sessions (Song et al., 2021), shortening sessions (Moss et al., 2015), adapting movement meditations to account for the age of the participants (Zang et al., 2015) and the integration of Zen stories and Vipassana meditations (Franco et al., 2017).

Table 1. Summary of included studies

AUTHOR, YEAR (COUNTRY)	STUDY DESIGN/ CONTROL	PARTICIPANTS	POPULATION & SETTING	INTERVENTION TYPE AND DURATION	PSYCHOLOGICAL OUTCOMES (MEASURES)
AHMADPANAH ET AL., 2017 (IRAN)	Randomised controlled trial Control: physical leisure activities	N= 34 (100% female) Mean age= 69.23 years (SD= 4.35) Age range= 65-85	Clinical population Participants met diagnostic criteria for Major Depressive Disorder as diagnosed by DSM-V	Adapted group MBI (Detached Mindfulness and Attention Training Techniques) Twice weekly 60-90 min sessions for 4 weeks (8 sessions)	Primary outcome(s): **Anxiety (BAI)** Depression (GDS + MADRS) Secondary outcome(s): none
FRANCO ET AL., 2017 (SPAIN)	Randomised controlled trial Control: waitlist	N= 87 (56% female, 44% male) Mean age= 76.5 years (SD= 16) Age range= 66-82	Non-clinical community sample Students at the University for Seniors who chose a meditation course	Adapted group MBI (Flow meditation (Kabat-Zinn, 1990), Zen (Deshimaru, 2006) and Vipassana meditation (Hart, 1994), psychoeducation on increasing awareness 120 min group session for 7 weeks	Primary outcome(s): **Anxiety (PSWQ, MWS, WAQ)** Depression (GDS) Secondary outcome(s): none
LEVY, 2018 (USA)	Pre- post repeated measures (doctoral thesis) No control	N= 19 (84.21% female, 15.79% male) Mean age= 78.93 years (SD= 7.15) Age range= 60-89	Non-clinical residential sample Participants lived in a retirement community	Adapted group MBI (based on Kabat-Zinn (1990) including psychoeducation re mindfulness, stress cycle, coping and values, mindful meditation exercises, reflection) 75-90 min group sessions for 5 weeks	Primary outcome(s): **Anxiety (DASS-21)** Depression (DASS-21) Secondary outcome(s): Mindfulness (FFMQ) Psychological wellbeing (PWBS) Emotion regulation (CERQ)
MOSS ET AL., 2015 (USA)	Randomised controlled trial Control: waitlist	N= 39 (82% female, 18% male) Mean age= 82.0 years (SD= 7.2) Age range= 63-94	Non-clinical residential sample Participants lived in a retirement community	Adapted group MBSR (Kabat-Zinn, 1990 protocol) 120 mins once weekly for 8 weeks, plus 25 to 30 min daily individual practice	Primary outcome(s): Feasibility and acceptability of MBSR Secondary outcome(s): **Anxiety (BSI-18)** Depression (BSI-18) Quality of life (SF-36) Psychological flexibility (AAQ-II) Mindfulness (FFMQ) Self compassion (SCS)

SMART & SEGALOWIZ, 2017 (CANADA)	Randomised controlled trial Control: psychoeducation (cognitive aging, stress, mood and memory) + memory strategies.	N= 19 (39% female, 61% male) Mean age= 70.0 years (SD= 3.45) Age range= 65-80	Non-clinical community sample Participants recruited through radio and newspaper. 78% reported previous psychiatric illness	Adapted group MBI (manualised protocol "Wisdom mind" (Kabat- Zinn (1990), incorporating loving kindness meditation) 8 weekly group sessions with daily home practice	Primary outcome(s): **Anxiety (AMAS-E)** Mood regulation (NMR) Mindfulness (FFMQ) Secondary outcome(s): none
SONG ET AL., 2021 (CHINA)	Randomised controlled trial Control: Treatment as usual (routine medical care)	N= 120 (46.6% female, 53.4% male) Mean age= 69.95 years (SD= 9.35) Age range= 61-80	Non-clinical sample Participants had gastroesophageal reflux disease and were inpatients in a medical hospital. Participants were excluded if they had severe psychological difficulties.	Adapted MBSR (Kabat-Zinn 1990 protocol plus, COVID focused mindfulness techniques including recognition and acceptance of feelings) 30 min individual session every other day for 10 days (total 8 sessions)	Primary outcome(s): **Anxiety (DASS-21)** Depression (DASS-21) Secondary outcome(s): Mood State (POMS) Sleep (PSQI)
THILAKAN ET AL., 2020 (INDIA)	Randomised controlled trial Control: physical exercise	N= 22 (86% female, 14% male) Mean age= not reported* Age range= not reported* 55% of participants were >75 years	Non-clinical residential sample Participants lived in retirement communities. Participants were excluded if they suffered from severe depression, anxiety or stress as per the DASS-21 or suffered from panic anxiety according to ICD-10 criteria.	Group MBI (mindfulness meditation plus muscle relaxation and guided imagery) Delivered for 25 mins daily for 1 month	Primary outcome(s): **Anxiety (DASS-21, STAI)** Depression (DASS-21) Stress (DASS-21) Secondary outcome(s): none
TKATCH ET AL., 2017 (USA)	Pre- post repeated measures No control	N= 22 (82.6% female, 17.4% male) Mean age= 73 years (SD= not reported) Age range= not reported*	Non-clinical community sample Caregivers of community- dwelling older adults recruited from community centres	Adapted group MBI (mindfulness meditation, self-care and compassion psychoeducation) 8 weekly 60 minute group sessions delivered online	Primary outcome(s): Caregiver burden (ZBI) **Anxiety (GAD-7)** Stress (PSS) Loneliness (UCLA) Quality of Life (VR-12) Secondary outcome(s): none
VELA, 2006 (USA)	Pre- post repeated measures (doctoral thesis) Control: waitlist	N= 12 (91.6% female, 8.4% male) Mean age= 83 years (SD= 5.9) Age range= 73-92	Non-clinical residential sample Participants lived in a retirement community with no known existing mental health conditions	Group MBI (relaxation exercises based on Silva Method (Silva & Miele, 1977) and mindful meditation exercises) 20 mins twice daily for 4 weeks Control Group- waitlist control	Primary outcome(s): **Anxiety (BAI)** Depression (GDS) Other outcome measures- Spiritual wellbeing (DSES)

YOUNG & BAIME, 2010 (USA)	Pre-post repeated measures No control	N= 141 (41% female, 59% male) Mean age= 65.3 years (SD= 5.4) Age range= not reported*	Non-clinical community sample Students undertaking a mindfulness course through the University of Pennsylvania	Group MBSR (Kabat-Zinn, 1990 protocol) 8 weekly 3.5 hour group sessions. Daily home practice for up to 45 mins	Primary outcome(s): Mood States (POMS)- **Anxiety measured through POMS subscale** Secondary outcome(s): none
ZHANG ET AL., 2015 (CHINA)	Randomised controlled trial Control: waitlist	N= 60 (41.2% female, 58.8% male) Mean age= 78.1 years (SD= 2.89) Age range= not reported*	Clinical sample Participants met DSM-IV criteria for insomnia	Group MBSR (Kabat-Zinn, 1990 protocol) 2 hours a week for 8 weeks plus 0.5 day retreat. Daily practice for up to 45 mins	Primary outcome(s): Sleep (PSQI) **Anxiety (SAS)** Depression (GDS) Secondary outcome(s): none

Note. * Where authors did not report the mean age or age range of participants, their inclusion criteria indicated that participants conformed to the inclusion criteria of the present review (i.e. over 60 years of age).

AAQ-II= Acceptance and Action Questionnaire, AMAS-E= Adult Manifest Anxiety Scale- Elderly Version, BAI= Beck Anxiety Inventory, BSI-18= Brief Symptom Inventory, CERQ= Cognitive Emotion Regulation Questionnaire, DASS-21= Depression Anxiety and Stress Scales, DSES= Daily Spiritual Experience Scale, FFMQ= Five Facets Mindfulness Questionnaire, GDS= Geriatric Depression Scale, MADRS= Montgomery-Asberg Depression Rating Scale, MWS= Meta-Worry Scale, NMR= Negative Mood Regulation Scale, POMS= Profile of Mood States, PSQI= Pittsburgh Sleep Quality Index, PSS= Perceived Stress Scale, PSWQ= Penn State Worry Questionnaire, PWBS= Ryff's Psychological Well-Being Scale, SAS= Self-rating Anxiety Scale, SCS= Self- Compassion Scale, SF-36= Short Form Health Survey, STAI= State and Trait Anxiety Inventory, UCLA= The UCLA Loneliness Scale, VR-12= Veteran's RAND, WAQ= Worry and Anxiety Questionnaire, ZBI= Zarit Burden Interview

3.3. Participant Characteristics

The number of participants in the studies ranged from 12 to 141 and totalled 575, with 56.7% all of participants reported as female. Four studies reported a range of 39-46.6% female participants with the remaining seven studies reporting between 56 -100% of the participants as female. Where it was reported, the mean age of participants ranged from 65.3- 83 years. Six of the studies included participants classed as the oldest-old (>80 years old). Just four of the studies reported the ethnicity of participants, which were homogeneous in ethnicity with 100% Caucasian participants.

3.4. Intervention Duration and Setting

Overall, studies featured interventions that were delivered over multiple sessions, with large variability in the number and length of sessions. Six of the studies featured interventions which were delivered over eight sessions, however the number of sessions across all the studies varied greatly from five (Levy, 2018) to 54 sessions (Vela, 2006). The frequency of sessions ranged from twice daily to once weekly, with the range in duration of sessions between 25 minutes and 120 minutes.

The majority of the interventions included in the studies were delivered in a group format. Only one was delivered to participants individually, a MBSR intervention for inpatients with gastroesophageal reflux disease (Song et al., 2021). This perhaps reflects the nature of the structured mindfulness-mediation interventions, such as MBSR, which were developed to be delivered in a group setting. Interestingly, one intervention was delivered online (Tkatch et al., 2017) whilst the rest were delivered face-to-face.

In terms of the intervention delivery, five of the studies did not report the job title or qualifications of the individual who delivered the mindful meditation intervention. Two studies reported their interventions were delivered by trained or trainee clinical psychologists (Ahmadpanah et al., 2017; Levy, 2018), two were delivered by certified mindfulness or MBSR teachers (Moss et al., 2018; Tkatch et al., 2017; Zhang et al., 2015) and Vela (2006) reported that the intervention facilitator had attended a mindfulness course. This suggests a wide variation in levels of training received by intervention facilitators.

Five studies recruited participants from a community or retirement community setting. Two studies recruited from a clinical sample, with Zhang et al. (2015) recruiting participants meeting the DSM-IV criteria for insomnia and Ahmadpanah et al. (2017) recruiting women meeting the DSM-V criteria for Major Depressive Disorder. Two studies recruited their participants through a university meditation or mindfulness course (Franco et al., 2017; Young & Baime, 2010), with Young & Baime (2010) reporting that 11% of their overall sample had significant clinical anxiety at baseline. One study

involved participants who were inpatients in a medical hospital being treated for gastroesophageal reflux disease (Song et al., 2021). The participants in Tkatch et al.'s (2017) study were caregivers of community dwelling older adults and were recruited through community carers' centres. Four of these studies stated that they excluded potential participants if they reported "significant" or "severe" mental health conditions.

3.5. Outcome Measures

A variety of outcome measures were used to evaluate anxiety (see Table 1) and these were all self-report measures. The most commonly used anxiety measure was the Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995), utilised by three of the studies. Both the Beck Anxiety Inventory (BAI; Beck, Epstein, Brown, & Steer, 1988) and the Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 1981) were used by two studies each. Only Smart & Segalowiz (2017) used an outcome measure specifically developed for the older adult population (Adult Manifest Anxiety Scale- Elderly Version). However, most of the other measures used have been validated in the older adult population. Only the Self-report Anxiety Scale (SAS; Zung, 1971) used by Zhang et al. (2015) does not appear to have been validated in an older adult population. A variety of other psychometric variables were measured alongside anxiety, including depression, mindfulness, self-compassion, quality of life and sleep.

3.6. Effectiveness of MBI on Anxiety

Findings are promising for the effectiveness of mindfulness meditation interventions on anxiety in the older adult population. Table 2 shows the anxiety outcomes of each study alongside the anxiety measure used and effect sizes.

Four studies reported significant improvements on measures of anxiety compared to a control group (Ahmadpanah et al., 2017; Franco et al., 2017; Thilakan et al., 2020; Song et al., 2021). Ahmadpanah et al. (2017) compared a MBI to a physical activity control group in females with major depressive disorder (N= 34). The study found the MBI to be effective with a large effect size (*d*= 2.20) when compared to the control condition, which was maintained at follow up four weeks later.

Franco et al. (2017) found large effects favouring the MBI when compared to the waiting list control group on the Penn State Worry Questionnaire (*d*= 1.03), the Meta Worry Scale (*d*= 0.82) and the Worry and Anxiety Questionnaire (*d*= 1.15). This study was conducted with a non-clinical sample of community dwelling older adults (N= 87) undertaking a university meditation course and used a mixture of different meditations drawn from MBSR, Zen stories, and Vipassana meditations, making it difficult to determine which of these had the greatest effect.

The study by Thilakan et al. (2020) reported a large effect of their MBI compared to a physical activity control group (*d*= 0.96) in a small sample (N= 22) of older adults living in a retirement community. The authors reported they had devised their intervention for use within the study and reported it contained a mixture of relaxation techniques, guided imagery and breathing meditations providing many confounding factors which should be considered when interpreting the highly significant results.

Song et al. (2021) reported a significant but small effect (*d*= 0.38) of their individually delivered MBSR intervention compared to treatment as usual. This study involved a medical sample of inpatients with gastroesophageal reflux disease (N= 120) and followed the MBSR protocol whilst integrating "COVID focused meditations to aid with the acceptance of feelings".

Two studies without a control condition reported significant pre- to post- intervention improvements on measures of anxiety (Tkatch et al., 2017; Young & Baime, 2010). Tkatch et al. (2017) investigated the effectiveness of a MBI for older caregivers in a small sample (N= 22). They found significant decreases in levels of anxiety post- intervention. Similarly, Young and Baime (2010) reported significant post- intervention improvements in levels of anxiety following weekly MBSR. This study was conducted with a larger sample (N=141) of community dwelling older adults undertaking a university-based mindfulness course.

A further study did not find significant results in the intervention group compared to the control condition but did report significant within group changes (i.e., pre- to post- intervention improvements) in levels of anxiety (Smart and Segalowiz, 2017). This study involved an active control condition of psychoeducation and the requirement of controls to practise daily memory strategies. This was the most active control condition of the studies included in the review. Compared to the intervention of a MBI, there was no significant differences in anxiety scores between the groups. However, the authors reported significant decreases in anxiety within the intervention group.

The final four studies did not report any significant difference in levels of anxiety (Levy, 2018; Moss et al., 2015; Vela, 2006; Zhang et al., 2015). Due to a small sample size (N=19) and significant pre-intervention differences in anxiety scores between the intervention and control conditions, Levy (2018) chose not to examine or report the effects of the MBI in community based older adults.

Table 2. Summary of between-group and within group anxiety effect sizes

STUDY AND ANXIETY MEASURE(S)	BETWEEN-GROUP DIFFERENCES (EFFECT SIZE)	WITHIN-GROUP CHANGES
AHMADPANAH ET AL., 2017		
BAI	In favour of intervention post- treatment (*d*= 2.20) and FU (*d*= 2.33)	-
FRANCO ET AL., 2017		
PSWQ	In favour of intervention post treatment (*d*= 1.03)	-
META WORRY SCALE	In favour of intervention post treatment (*d*= 0.82)	-
WAQ	In favour of intervention post treatment (*d*= 1.15)	-
LEVY, 2018		
DASS-21- A	n/a	Author unable to conclude
MOSS ET AL., 2015		
BRIEF SYMPTOM INVENTORY	ns	ns
THILAKAN ET AL., 2020		
DASS-21- A	In favour of intervention post treatment (*d*= 0.96)	-
SMART & SEGALOWIZ, 2017		
AMAS- ELDERLY VERSION	ns	Intervention & ctrl group improvements from pre -to post- treatment
SONG ET AL., 2021		
DASS-21	In favour of intervention post treatment (*d*= 0.38)	-
TKATCH ET AL., 2017		
GAD-7	n/a	Significant intervention improvement from pre- to post- treatment
VELA, 2006		
BAI	ns	ns
YOUNG & BAIME, 2010		
POMS-SF	n/a	Significant intervention improvement from pre- to post- treatment
ZHANG ET AL., 2015		
SAS	ns	ns

Note. ns= non-significant, n/a= not applicable due to study design, FU= follow-up, AMAS-E= Adult Manifest Anxiety Scale- Elderly Version, BAI= Beck Anxiety Inventory, BSI-18= Brief Symptom Inventory,DASS-21= Depression Anxiety and Stress Scales, MWS= Meta-Worry Scale, POMS= Profile of Mood States, PSWQ= Penn State Worry Questionnaire, SAS= Self-rating Anxiety Scale, WAQ= Worry and Anxiety Questionnaire

Effect sizes are Cohen's d*, where those over 0.20 are considered small, those over 0.50 considered medium and large effect sizes are over 0.80 (Cohen, 1988).*

3.7. Additional Findings

Five of the included studies also reported significant decreases in levels of depression post intervention (Ahmadpanah et al., 2017; Franco et al., 2017; Song et al., 2021; Thilakan et al., 2020; Zhang et al., 2015). Ahmadpanah et al. (2017) used both self-report and independent rating scales to measure depression, the only study included to use an objective measure.

Young & Baime (2010) reported significant improvements in overall mood scores, as well as significant improvements on all subscales of the POMS post intervention.

The two studies which measured sleep quality both reported significant improvements in the mindfulness meditation intervention condition (Song et al., 2021; Zhang et al., 2015). Although, it is worth highlighting the small effect size (*d*= 0.06) reported for sleep quality in the study by Zhang et al. (2015). In contrast, the effect size reported by Song was large (*d*= 1.04).

Other significant psychological outcomes reported included decreased levels of caregiver burden, stress and increased quality of life following the MBI in the population of older caregivers (Tkatch et al., 2017). Finally, Moss et al. (2015) reported significant improvements in MBSR participants' levels of psychological flexibility (*d*= 0.43) and acceptance of their quality of life (*d*= 0.75) when compared with the control condition.

3.8. Quality of Papers

Further details of the critical appraisal of studies is shown in Appendix B. The overall quality of the included RCTs ranged from moderate to high, with all papers evaluated meeting more than 60% of the applicable quality criteria. Criteria relating to blinding of the treatment assigment for both participants and facilitators was not deemed applicable due to the nature of the intervention. Six of the seven RCTs did not report whether their allocation of participants to treatment groups was concealed. Only Smart & Segalowitz (2017) reported keeping participants and group leaders blind to the diagnositic group of participants, where healthy controls and those with subjective cognitive decline were mixed. Two or the seven studies reported measures taken to prevent bias when assessing outcomes (Ahmadpanah et al., 2017; Moss et al., 2015). Whilst the majority of studies treated their intervention groups identically, in Smart & Segalowitz's RCT their active control condition, a psychoeducation group, consisted of five sessions compared to the eight sessions of MBI offered to the treatment group.

Quasi-experiemental studies were also of moderate to high quality, with all four studies meeting at least 78% of the applicable quality criteria. Two of the studies did not include a control group (Tkatch

et al., 2017; Young & Baime, 2010), and one reported significant pre-intervention differences between the control and intervention group, leading to the inability to draw conclusions on the effectivenss of the intervention.

3.9. RE-AIM Analysis

Table 3 provides the proportion of studies reporting on the RE-AIM five dimensions and 21 indicators. Further detail of the RE-AIM analysis is shown in Appendix C.

Reach was the second most reported dimension with 67.3% of studies reporting the relevant indicators of inclusion/exclusion criteria and attendance to the intervention. However none of the studies indicated the degree to which their samples were representative of a wider population, especially relevant in studies with a much higher proportion of females compared to males. With an average of 84.1% indicators reported, *efficacy* was the most reported dimension across the studies. All studies used appropriate outcome measures and most measured negative as well as positive outcomes relating to the intervention. Where studies were less consistant in their reporting was in relation to attrition with seven of the eleven studies reporting this; however, all other efficacy indicators were reported by at least nine of the studies. *Adoption* was poorly reported with 36.4% of indicators being met across the studies. Only one study reported the method used to identify intervention facilitators (Vela, 2006), and none of studies reported inclusion and exclusion criteria relating to the facilitator or the adoption. *Implementation* was similarly poorly reported, also with 36.4% of being met. Whilst all studies reported the frequency and duration of the intervention, only one reported how closely it had followed the intervention protocol and none reported the cost of the intervention. Finally, *maintenance* was the least reported dimension with just 2.7% of indicators being met across studies. No outcomes were assessed at six months following the intervention and there were no reports of the maintainance of adherence at long term after completing the research study. One study mentioned the cost effectivness of continuing the intervention beyond the study and this was in relation to the intervention being delivered online (Tkatch et al., 2017).

Table 3. Proportion of eleven studies in the review reporting on RE-AIM (Reach, Efficacy, Adoption, Implementation, Maintenance) dimensions across 21 indicators.

INDICATOR	STUDIES REPORTING, N (%)
REACH	
1. METHOD TO IDENTIFY TARGET POPULATION	11 (100)
2. INCLUSION CRITERIA	8 (72.7)
3. EXCLUSION CRITERIA	8 (72.7)
4. PARTICIPATION RATE	10 (90.9)
5. REPRESENTATIVENESS	0 (0)
AVERAGE ACROSS REACH INDICATORS	**7.4 (67.3)**
EFFICACY	
6. MEASURES/ RESULTS FOR AT LEAST ONE FOLLOW-UP	11 (100)
7. INTENT-TO-TREAT ANALYSIS	9 (81.8)
8. QUALITY OF LIFE OF POTENTIAL NEGATIVE OUTCOMES	10 (90.9)
9. PERCENT ATTRITION	7 (63.6)
AVERAGE ACROSS EFFICACY INDICATORS	**9.3 (84.1)**
ADOPTION	
10. DESCRIPTION OF INTERVENTION LOCATION	11 (100)
11. DESCRIPTION OF STAFF WHO DELIVERED INTERVENTION	6 (54.5)
12. METHOD TO IDENTIFY STAFF WHO DELIVERED INTERVENTION (TARGET DELIVERY AGENT)	1 (9.1)
13. LEVEL OF EXPERTISE OF DELIVERY AGENT	6 (54.5)
14. INCLUSION/ EXCLUSION OF DELIVERY AGENT	0 (0)
15. ADOPTION RATE OF DELIVERY AGENT	0 (0)
AVERAGE ACROSS ADOPTION INDICATORS	**4 (36.4)**
IMPLEMENTATION	
16. INTERVENTION DURATION AND FREQUENCY	11 (100)
17. EXTENT PROTOCOL DELIVERED AS INTENDED (%)	1 (9.1)
18. MEASURES OF COST OF IMPLEMENTATION	0 (0)
AVERAGE ACROSS IMPLEMENTATION INDICATORS	**4 (36.4)**
MAINTENANCE	
19. ASSESSED OUTCOMES AT 6 MONTHS OR OVER POST INTERVENTION	0 (0)
20. INDICATORS OF PROGRAM-LEVEL MAINTENANCE OF INTERVENTION	0 (0)
21. MEASURES OF COST MAINTENANCE	1 (9.1)
AVERAGE ACROSS MAINTENANCE INDICATORS	**0.3 (2.7)**

4. Discussion

The objective of this systematic review was to explore the effectiveness of mindfulness meditation interventions on levels of anxiety in older adults. Furthermore, it aimed to critically evaluate the included studies and explore their transferability to clinical practice. Eleven studies were identified from the search process and were evaluated with both the Joanna Briggs Critical Appraisal Tool (Johanna Briggs Institute, 2017) and the RE-AIM framework (Glasgow et al., 1999).

In regard to the first aim, the present study found preliminary evidence for the effectiveness of mindful meditation interventions in the older adult population. Results showed significant improvements in the intervention condition in seven of the eleven studies. These results were across

a range of populations, including women with major depressive disorder (Ahmadpanah et al., 2017), non-clinical community samples (Franco et al., 2017; Smart & Segalowiz, 2017; Young & Baime, 2010), medical inpatients (Song et al., 2021) and caregivers (Tkatch et al., 2017). In regard to the remaining four studies included in this review, one study was unable to draw conclusions due to methodological limitations (Levy, 2018) and three did not identify any significant effects of their intervention on anxiety.

This review built on the findings of Li & Bressington (2019) whose review was inconclusive, due to a limited number of studies. Unlike the review by Li & Bressington (2019) which focused only on studies using MBSR, the present review included a broader range of mindfulness meditation interventions and chose to focus soley on anxiety as the outcome variable. The current review also employed stricter inclusion criteria in regards to age, with the Li & Bressington (2019) review including studies that referred to participants as older adults, resulting in studies including participants as young as 52 years. The present study provides more consistent evidence to suggest that mindfulness meditation interventions appear to have a positive effect on the reduction of anxiety in older adults and thus is similar to results of similar reviews with younger adults (Khoury et al., 2015).

Although the results indicate that mindfulness meditation interventions have the potential to reduce anxiety in older adults, there were four reviewed studies that were not in keeping with this result. This finding is similar to reviews investigating the effects of mindfulness mediation interventions on other psychological variables including depression (Reangsing, Rittiwong, & Schneider, 2021) and wellbeing (Geiger et al., 2016), where a proportion of studies do not report significant findings. One commonly reported suggestion for the lack of significant findings within the older adult population is the low rates of adverse mental health in community samples at baseline (Steptoe et al., 2015). Low rates of anxiety pre-intervention were cited by Moss et al. (2015) as one of the potential reasons for the lack of significant findings in their study. Interestingly, two of the studies reporting insignificant or inconclusive findings were doctoral theses (Levy, 2018; Vela, 2006). This perhaps highlights the issue of publication bias, in that doctoral theses will be published regardless of findings, whereas journal articles are more likely to contain significant results (Francis, 2012). What these insignificant findings highlight is the need for replication of the studies included in this review, as well a move to consider insignificant findings as just as important as significant ones.

4.1. Methodological Quality and Transferability of Findings

With regard to the methodological quality of the studies included in this review, overall the quality of the papers was deemed moderate to high. Strengths of the papers included randomisation of participants into treatment groups, the use of reliable outcome measures and the reporting of appropriate statistical analysis. However, despite the overall strengths, there were a number of methodological weaknesses and biases identified within the studies. The most notable of these was the lack of control group in three of the eleven studies, making the results less certain as factors such as non- controlled variables or the passage of time are not accounted for. Furthermore, one study, which did utilise an active control condition, provided its participants with a different number of psychoeducation sessions than those received by the intervention group (Smart & Segalowitz, 2017). This means the potential positive effects received by the intervention group, such as increased contact time and social effects of the group, are unaccounted for and may skew the results.

A further methodological weakness concerned the outcome measures used. All anxiety outcomes in the included studies were assessed using self-report measures. Using self-report measures can result in response-shift bias, whereby participants are more likely to report improvement following engagement with an intervention (Howard, 1980). One study included in the present review did use an independent rating scale to measure depression (Ahmadpanah et al., 2017), however none of the studies employed independent rating to measure anxiety.

Sample sizes varied across the included studies with many lacking sufficient power for between-group analyses. Two of the studies with non-significant findings had very low sample sizes ($n<19$), the two lowest of the included studies, resulting in reduced power and preventing the findings from being reliably extrapolated. A larger sample size reduces the risk of sampling bias, improving effect size estimates and reducing the potential for finding an effect where one does not exist (Anderson, Kelley, & Maxwell, 2017). However, it should be recognised that it is often difficult to achieve large sample sizes in clinical research, especially within the older adult population. Therefore, alternative study designs, such as multiple-baseline single case studies, should be considered when exploring the effectiveness of mindfulness meditation interventions on anxiety in older adults.

The RE-AIM analysis in this review highlights several challenges in transferring research findings in studies of mindfulness meditation to clinical interventions that can be delivered on a wider scale. The findings from the RE-AIM analysis conducted in this study are consistent with results of reviews concerning mindfulness interventions (Russell, Ugalde, Milne, Austin, & Livingston, 2018) and the

literature in general (Glasgow et al., 2019). That is to say that adoption and maintenance factors are often underreported, as found in this review. The present study also found poor reporting in the implementation domain. The study by Moss et al. (2015) performed the best in the RE-AIM analysis, meeting 61.9% of the indicators. Young & Baime's (2010) study met only 23.8% of the indicators, performing the worst in terms of indicators of clinical transferability.

The adoption criteria is arguably more important in psychological intervention studies as opposed to pharmacological interventions, as the impact of the setting and delivery staff are likely to be greater (Wang et al., 2019). Only six of the studies included in the present review reported the job title or qualifications of the individual delivering the intervention, crucial information when considering the implementation of mindfulness meditation interventions beyond a research setting. Furthermore, none of the papers detailed how the delivery agents were chosen. Considering that the evidence-base suggests that the therapeutic relationship contributes towards the effectiveness of psychological interventions (Burlingame, Fuhriman, & Johnson, 2001) it seems imperative that the facilitators should be psychologically informed and aware of their own impact on participants. Hence, researchers should report factors relating to the delivery agents to increase transparency.

Implementation factors were poorly reported in the studies within this review. Although all studies did report the duration and frequency of their intervention, all bar one reported the extent to which the protocol was delivered as intended. Within this review many of the studies reported they used an adapted MBSR protocol however, not all studies detailed what these adaptions were. This information is key when considering the effectiveness of an intervention and its transferability. Similarly, none of the studies reported the cost of the intervention implementation. Arguably, costs are far less in psychological interventions compared to pharmacological interventions; however, the cost of running an intervention is still an important factor considered by policy makers and service managers (Yates, 2020).

Maintenance is also a critical factor when considering the effectiveness of a psychological intervention. A methodological weakness seen across studies was the lack of follow-up post intervention. Only one study gathered data from participants at a time point following immediate completion of the intervention (Ahmadpanah et al., 2017). Post-intervention follow-up can provide valuable information about the long-term benefits and consequences of an intervention and is important when considering overall effectiveness (Llewellyn-Bennett, Bowman, & Bulbulia, 2016). For this reason, it is hard to determine the true effectiveness of the majority of the studies included

in this review. Despite this, the results of this review add to a relatively new area of research and overall are promising for the treatment of anxiety with mindfulness meditation interventions in older adults.

4.2. Implications for Clinical Practice

Although positive effect has been demonstrated regarding the effectiveness of mindfulness meditation interventions on anxiety amongst older adults, the evidence remains inconclusive. Results included in this review suggest that mindfulness mediation interventions can be effective at reducing anxiety in this population, especially when compared to no intervention. Furthermore, there appears to be positive effects of mindfulness meditation interventions on other psychological outcomes including depression, sleep and caregiver burden. The fact that effects have been shown in a number of settings and both with clinical and non-clinical populations is promising for the generalisability of mindfulness meditation interventions. As discussed previously, there is a growing evidence base for third wave interventions within the older adult population (Davison et al., 2017; Moghadam et al., 2020). Interventions, ACT and CFT, which are proving to be effective with this population, often require to be delivered by highly specialised clinicians. The interventions included within the present review can be delivered by individuals with far less training, and preferably within a group setting, ensuring both cost and time effectiveness.

Additionally, mindfulness meditation interventions within this study were found to be effective at reducing anxiety levels in non-clinical populations of older adults. These results suggest that mindfulness meditation interventions have the potential to be used as a preventative measure, which may prevent individuals reaching clinical levels of anxiety. The accessibility of community run group-based mindfulness meditation interventions compared to individual traditional psychotherapy also means that it has the potential to benefit individuals who may not ordinarily have contact with psychological services. This is especially relevant when considering the older adult population, who are known to be less likely to present to psychological services, especially since the onset of the COVID-19 outbreak (Wong et al., 2020).

Furthermore, the use of online intervention delivery in Tkatch et al.'s (2017) study suggests tentative evidence for the acceptability of online adaptations of mindfulness meditation interventions in this population. This has the potential to further increase accessibility for a population who may struggle with mobility or who are unable to attend in-person interventions due to caring or other responsibilities.

4.3. Limitations and Strengths of Present Review

The search and screening process was conducted manually by the lead author and although great care was taken, there is still a risk that studies were missed and therefore not included in the review. Furthermore, this study focused solely on quantitative and mixed method studies and therefore does not represent all studies that have been conducted in this topic area. Additionally, this study did not include articles published in a language other than English.

The range of outcome measures used to evaluate anxiety was broad and meant that evaluation was complex and the comparison of results across studies is done with caution. Similarly, the broad range of samples used and settings that the interventions took place in makes it hard to compare findings.

Insufficient information was available to calculate effect sizes for within group changes (i.e., pre- and post- intervention) resulting in the inability to compare effects in the studies without control conditions. Attempts were made to retrieve this information from the authors.

The use of an external researcher to independently quality appraise studies improves the reliability and validity of the review. Furthermore, the inclusion of doctoral theses aimed to reduce the risk of publication bias whilst still ensuring included studies were peer reviewed, and therefore of a high methodological standard.

4.4. Future Research

Future research of high methodological quality is required to build upon the findings of those included in this study. To achieve this, future studies should use larger sample sizes, utilising power calculations to ensure adequate power is reached. Furthermore, the use of control conditions should be employed to add greater understanding of the effectiveness of the interventions. Alongside this, future studies should include follow-up evaluations to determine whether any significant effects are maintained. Building on the results of the aforementioned online delivery of mindfulness meditation interventions, future research should compare remotely delivered interventions to the same intervention delivered in person.

It was clear from the studies included in this review that a variety of protocols were followed for the delivery of mindfulness meditation interventions. Additionally, in some studies the intervention

included potentially confounding elements, such as relaxation and guided visualisation. Although the adaptations to the protocol in some studies were deemed beneficial for the population, this adds a further layer of complexity when determining effectiveness. Therefore, future research should use standardised and protocol-based interventions, which do not include confounding elements.

One important finding in the review conducted by Reansing et al. (2021) exploring the effects of mindfulness mediation intervention on levels of depression in older adults, was the difference in effects found between Asian populations compared to those from Europe and North America. In the present study it was not possible to compare populations as so few studies reported the participants ethnicity or cultural make-up of their samples. Future research should explore the effect of culture on the impact of mindfulness meditation interventions by collecting further demographic information from participants.

4.5. Conclusion

Findings from this review suggest that mindfulness meditation interventions have the potential to reduce levels of anxiety in older adults. However, the quality and breadth of the research to date means these findings should be interpreted with caution. Further research is needed to produce high quality studies focusing solely on mindfulness meditation interventions in older adults, following a strict protocol. Control conditions should be used to ensure accurate evaluation of the effects of the intervention on anxiety. However, the initial results provide positive indications that mindfulness meditation interventions could benefit both clinical and non-clinical populations of older adults in a variety of settings.

5. References

Ahmadpanah, M., Akbari, T., Akhondi, A., Haghighi, M., Jahangard, L., Bahmani, D. S., . . . Brand, S. (2017). Detached mindfulness reduced both depression and anxiety in elderly women with major depressive disorders. *Psychiatry Research, 257*, 87-94. doi:10.1016/j.psychres.2017.07.030

Aldwin, C. M., Yancura, L., & Lee, H. (2021). Stress, coping, and aging. In *Handbook of the Psychology of Aging* (pp. 275-286). Elsevier.

Anderson, S. F., Kelley, K., & Maxwell, S. E. (2017). Sample-size planning for more accurate statistical power: A method adjusting sample effect sizes for publication bias and uncertainty. *Psychological Science, 28*(11), 1547-1562. doi:10.1177/0956797617723724

Andreas, S., Schulz, H., Volkert, J., Dehoust, M., Sehner, S., Suling, A., . . . Da Ronch, C. (2017). Prevalence of mental disorders in elderly people: the European MentDis_ICF65+ study. *The British Journal of Psychiatry, 210*(2), 125-131. doi:10.1192/bjp.bp.115.180463

Balsamo, M., Cataldi, F., Carlucci, L., & Fairfield, B. (2018). Assessment of anxiety in older adults: a review of self-report measures. *Clinical Interventions in Aging, 13*, 573. doi:10.2147/CIA.S114100

Beaunoyer, E., Landreville, P., & Carmichael, P.-H. (2019). Older adults' knowledge of anxiety disorders. *The Journals of Gerontology: Series B, 74*(5), 806-814. doi:10.1093/geronb/gbx128

Boone, M. S., Mundy, B., Morrissey Stahl, K., & Genrich, B. E. (2015). Acceptance and commitment therapy, functional contextualism, and clinical social work. *Journal of Human Behavior in the Social Environment, 25*(6), 643-656. doi:10.1080/10911359.2015.1011255

Bryant, C., Jackson, H., & Ames, D. (2008). The prevalence of anxiety in older adults: methodological issues and a review of the literature. *Journal of Affective Disorders, 109*(3), 233-250. doi:10.1016/j.jad.2007.11.008

Burlingame, G. M., Fuhriman, A., & Johnson, J. E. (2001). Cohesion in group psychotherapy. *Psychotherapy: Theory, Research, Practice, Training, 38*(4), 373. doi:10.1037/0033-3204.38.4.373

Chiesa, A., & Malinowski, P. (2011). Mindfulness-based approaches: Are they all the same? *Journal of Clinical Psychology, 67*(4), 404-424. doi:10.1002/jclp.20776

Corbett, C., Egan, J., & Pilch, M. (2019). A randomised comparison of two stress control programmes: progressive muscle relaxation versus mindfulness body scan. *Mental Health & Prevention, 15*, 200163. doi:10.1016/j.mph.2019.200163

Coupland, C., Dhiman, P., Morriss, R., Arthur, A., Barton, G., & Hippisley-Cox, J. (2011). Antidepressant use and risk of adverse outcomes in older people: population based cohort study. *British Medical Journal, 343*, 4551. doi:10.1136/bmj.d4551

Davison, T. E., Eppingstall, B., Runci, S., & O'Connor, D. W. (2017). A pilot trial of acceptance and commitment therapy for symptoms of depression and anxiety in older adults residing in long-term care facilities. *Aging & Mental Health, 21*(7), 766-773. doi:10.1080/13607863.2016.1156051

Feigenbaum, J. (2007). Dialectical behaviour therapy: An increasing evidence base. *Journal of Mental Health, 16*(1), 51-68. doi:10.1080/09638230601182094

Forbes, M., Crome, E., Sunderland, M., & Wuthrich, V. (2017). Perceived needs for mental health care and barriers to treatment across age groups. *Aging & mental health, 21*(10), 1072-1078. doi:10.1080/13607863.2016.1193121

Francis, G. (2012). Publication bias and the failure of replication in experimental psychology. *Psychonomic Bulletin & Review, 19*(6), 975-991. doi:10.3758/s13423-012-0322-y

Franco, C., Amutio, A., Mañas, I., Gázquez, J. J., & del Carmen Pérez-Fuentes, M. (2017). Reducing anxiety, geriatric depression and worry in a sample of older adults through a mindfulness training program.*Terapia Psicológica, 35*(1), 71-79. doi:10.4067/S0718-48082017000100007

Gaglio, B., Phillips, S. M., Heurtin-Roberts, S., Sanchez, M. A., & Glasgow, R. E. (2014). How pragmatic is it? Lessons learned using PRECIS and RE-AIM for determining pragmatic characteristics of research. *Implementation Science, 9*(1), 1-11. doi:10.1186/s13012-014-0096-x

Geiger, P. J., Boggero, I. A., Brake, C. A., Caldera, C. A., Combs, H. L., Peters, J. R., & Baer, R. A. (2016). Mindfulness-based interventions for older adults: A review of the effects on physical and emotional well-being. *Mindfulness, 7*(2), 296-307. doi:10.1007/s12671-015-0444-1

Gilbert, P. (2005). *Compassion: Conceptualisations, research and use in psychotherapy.* Routledge.

Glasgow, R. E., Harden, S. M., Gaglio, B., Rabin, B., Smith, M. L., Porter, G. C., . . . Estabrooks, P. A. (2019). RE-AIM planning and evaluation framework: adapting to new science and practice with a 20-year review. *Frontiers in Public Health, 7*, 64. doi:10.3389/fpubh.2019.00064

Glasgow, R. E., Vogt, T. M., & Boles, S. M. (1999). Evaluating the public health impact of health promotion interventions: the RE-AIM framework. *American Journal of Public Health, 89*(9), 1322-1327. doi:10.2105/AJPH.89.9.1322

Gloster, A. T., Rhoades, H. M., Novy, D., Klotsche, J., Senior, A., Kunik, M., . . . Stanley, M. A. (2008). Psychometric properties of the Depression Anxiety and Stress Scale-21 in older primary care patients. *Journal of Affective Disorders, 110*(3), 248-259. doi:10.1016/j.jad.2008.01.023

Goldberg, S. B., Tucker, R. P., Greene, P. A., Davidson, R. J., Wampold, B. E., Kearney, D. J., & Simpson, T. L. (2018). Mindfulness-based interventions for psychiatric disorders: A systematic review and meta-analysis. *Clinical Psychology Review, 59*, 52-60. doi:10.1016/j.cpr.2017.10.011

Gonçalves, D. C., & Byrne, G. J. (2012). Interventions for generalized anxiety disorder in older adults: systematic review and meta-analysis. *Journal of Anxiety Disorders, 26*(1), 1-11. doi:10.1016/j.janxdis.2011.08.010

Grossman, P., Niemann, L., Schmidt, S., & Walach, H. (2004). Mindfulness-based stress reduction and health benefits: A meta-analysis. *Journal of Psychosomatic Research, 57*(1), 35-43. doi:10.1016/S0022-3999(03)00573-7

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2009). *Acceptance and commitment therapy*. American Psychological Association.

Howard, G. S. (1980). Response-shift bias: A problem in evaluating interventions with pre/post self-reports. *Evaluation Review, 4*(1), 93-106. doi:10.1177/0193841X8000400105

Joanna Briggs Institute (Producer). (2017). Checklists for systematic review and research synthesis.

Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: past, present, and future. *Clinical Psychology: Science and Practice*, 10, 144-156. doi:10.1093/clipsy.bpg016

Kabat-Zinn, J., & Hanh, T. N. (2009). *Full catastrophe living: Using the wisdom of your body and mind to face stress, pain, and illness*. Delta.

Khoury, B., Sharma, M., Rush, S. E., & Fournier, C. (2015). Mindfulness-based stress reduction for healthy individuals: A meta-analysis. *Journal of Psychosomatic Research, 78*(6), 519-528. doi:10.1016/j.jpsychores.2015.03.009

Kogan, J. N., Edelstein, B. A., & McKee, D. R. (2000). Assessment of anxiety in older adults: current status. *Journal of Anxiety Disorders, 14*(2), 109-132. doi:10.1016/S0887-6185(99)00044-4

Levy, M. (2018). *An Examination of a Mindfulness-Based Intervention for Older Adults* [Doctoral thesis, Nova Southeastern University]. ProQuest Dissertations and Theses Global. Retrieved from: https://www.proquest.com/pqdtglobal/docview/2116163736/A99648A72BCF4684PQ/1?accountid=10673

Li, S. Y. H., & Bressington, D. (2019). The effects of mindfulness-based stress reduction on depression, anxiety, and stress in older adults: A systematic review and meta-analysis. *International Journal of Mental Health Nursing, 28*(3), 635-656. doi:10.1111/inm.12568

Linehan, M. M. (2015). *DBT® Skills Training: manuale*. Cortina.

Llewellyn-Bennett, R., Bowman, L., & Bulbulia, R. (2016). Post-trial follow-up methodology in large randomized controlled trials: a systematic review protocol. *Systematic Reviews, 5*(1), 1-7. doi:10.1186/s13643-016-0393-3

Lomas, T., Medina, J. C., Ivtzan, I., Rupprecht, S., & Eiroa-Orosa, F. J. (2019). Mindfulness-based interventions in the workplace: An inclusive systematic review and meta-analysis of their impact upon wellbeing. *The Journal of Positive Psychology, 14*(5), 625-640. doi:10.1080/17439760.2018.1519588

Longmore, R. J., & Worrell, M. (2007). Do we need to challenge thoughts in cognitive behavior therapy? *Clinical Psychology Review, 27*(2), 173-187. doi:10.1016/j.cpr.2006.08.001

Maltais, M., Bouchard, G., & Saint-Aubin, J. (2019). Mechanisms of mindfulness: The mediating roles of adaptive and maladaptive cognitive factors. *Current Psychology, 38*(3), 846-854. doi:10.1007/s12144-017-9665-x

Moghadam, K. K., Baharvandi, B., & Rashidi, H. H. (2020). The Effectiveness of compassion-focused therapy on ambiguity tolerance and death anxiety in the elderly. *Aging, 6*(1), 13-26. Retrieved from: https://jap.razi.ac.ir/mobile/article_1446_7f774fde0f3013c195d5f094bbb34968.pdf

Moss, A. S., Reibel, D. K., Greeson, J. M., Thapar, A., Bubb, R., Salmon, J., & Newberg, A. B. (2015). An adapted mindfulness-based stress reduction program for elders in a continuing care retirement community: Quantitative and qualitative results from a pilot randomized controlled trial. *Journal of Applied Gerontology, 34*(4), 518-538. doi:10.1177/0733464814559411

National Institute for Health and Care Excellence [NICE]. (2011). *Generalised anxiety disorder and panic disorder in adults: management*. Retrieved from https://www.nice.org.uk/guidance/cg113/chapter/Key-priorities-for-implementation

Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., . . . Mulrow, C.D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *British Medical Journal, 372*(71). doi:10.1136/bmj.n71

Pierson, M. M., Roche, A. I., & Denburg, N. L. (2019). Mindfulness, experiential avoidance, and affective experience in older adults. *Journal of Contextual Behavioral Science, 14*, 32-36. doi:10.1016/j.jcbs.2019.08.007

Rapport, F., Clay-Williams, R., Churruca, K., Shih, P., Hogden, A., & Braithwaite, J. (2018). The struggle of translating science into action: foundational concepts of implementation science. *Journal of Evaluation in Clinical Practice, 24*(1), 117-126. doi:10.1111/jep.12741

Reangsing, C., Rittiwong, T., & Schneider, J. K. (2021). Effects of mindfulness meditation interventions on depression in older adults: A meta-analysis. *Aging & Mental Health, 25*(7), 1181-1190. doi:10.1080/13607863.2020.1793901

Russell, L., Ugalde, A., Milne, D., Austin, D., & Livingston, P. M. (2018). Digital characteristics and dissemination indicators to optimize delivery of internet-supported mindfulness-based interventions for people with a chronic condition: systematic review. *JMIR Mental Health, 5*(3), e9645. doi:10.2196/mental.9645

Segal, Z. V., & Walsh, K. M. (2016). Mindfulness based cognitive therapy for residual depressive symptoms and relapse prophylaxis. *Current Opinion in Psychiatry, 29*(1), 7. doi:10.1097/YCO.0000000000000216

Segal, Z. V., Williams, M., & Teasdale, J. (2018). *Mindfulness-based cognitive therapy for depression*. Guilford Publications.

Smart, C. M., & Segalowitz, S. J. (2017). Respond, don't react: The influence of mindfulness training on performance monitoring in older adults. *Cognitive, Affective, & Behavioral Neuroscience, 17*(6), 1151-1163. doi:10.3758/s13415-017-0539-3

Song, C., Zhang, Y., & Wu, Z. (2021). Effect of mindfulness-based stress reduction therapy on psychological status and sleep quality of elderly patients with gastroesophageal reflux disease during COVID-19 pandemic. *World Chinese Journal of Digestology*, 48-52. doi:10.11569/wcjd.v29.i1.48

Steptoe, A., Deaton, A., & Stone, A. A. (2015). Subjective wellbeing, health, and ageing. *The Lancet, 385*(9968), 640-648. doi:10.1016/S0140-6736(13)61489-0

Thilakan, P. (2020). Effectiveness of TIPER (Tailor Made Interventional Package to Enhance Relaxation) on Stress, Depression and Anxiety among Elders-A Pilot Study. *International Journal of Health Sciences and Research, 8*(3), 186-192. Retrieved from: https://d1wqtxts1xzle7.cloudfront.net/64027854/

Thomas, R., Chur-Hansen, A., & Turner, M. (2020). A systematic review of studies on the use of Mindfulness-Based Cognitive Therapy for the treatment of anxiety and depression in older people. *Mindfulness, 11*(7), 1599-1609. doi:10.1007/s12671-020-01336-3

Tkatch, R., Bazarko, D., Musich, S., Wu, L., MacLeod, S., Keown, K., . . . Wicker, E. (2017). A pilot online mindfulness intervention to decrease caregiver burden and improve psychological well-being. *Journal of Evidence-based Complementary & Alternative Medicine, 22*(4), 736-743. doi:10.1177/2156587217737204

Vela, R. H. (2004). *The effects of relaxation and meditation on assisted living residents, their neighbors, and the overall quality of life of the residential facility* [Doctoral thesis, The University of Kansas]. ProQuest Dissertations and Theses Global. Retrieved from: https://www.proquest.com/pqdtglobal/docview/305171564/465D85ED40454449PQ/1?accountid=10673

Wang, G., Albayrak, A., & van der Cammen, T. J. (2019). A systematic review of non-pharmacological interventions for BPSD in nursing home residents with dementia: from a perspective of ergonomics. *International Psychogeriatrics, 31*(8), 1137-1149. doi:10.1017/S1041610218001679

Wong, S. Y. S., Zhang, D., Sit, R. W. S., Yip, B. H. K., Chung, R. Y.-n., Wong, C. K. M., . . . Mercer, S. W. (2020). Impact of COVID-19 on loneliness, mental health, and health service utilisation: a prospective cohort study of older adults with multimorbidity in primary care. *British Journal of General Practice, 70*(700), e817-e824. doi:10.3399/bjgp20X713021

World Health Organisation. (2021a). *Aging and Health: October 2021*. Retrieved from https://www.who.int/news-room/fact-sheets/detail/ageing-and-health

World Health Organisation. (2021b). *Comprehensive Mental Health Action Plan 2013-2030*. Retrieved from https://www.who.int/publications/i/item/9789240031029

Wuthrich, V. M., Johnco, C. J., & Wetherell, J. L. (2015). Differences in anxiety and depression symptoms: comparison between older and younger clinical samples. *International Psychogeriatrics, 27*(9), 1523-1532. doi:10.1017/S1041610215000526

Wuthrich, V. M., Meuldijk, D., Jagiello, T., Robles, A. G., Jones, M. P., & Cuijpers, P. (2021). Efficacy and effectiveness of psychological interventions on co-occurring mood and anxiety disorders in older adults: A systematic review and meta-analysis. *International Journal of Geriatric Psychiatry, 36*(6), 858-872. doi:10.1002/gps.5486

Yang, Y. (2007). Is old age depressing? Growth trajectories and cohort variations in late-life depression. *Journal of Health and Social Behavior, 48*(1), 16-32. doi:10.1177/002214650704800102

Yates, B. T. (2020). Research on improving outcomes and reducing costs of psychological interventions: Toward delivering the best to the most for the least. *Annual Review of Clinical Psychology, 16*, 125-150. doi:10.1146/annurev-clinpsy-071519-110415

Young, L. A., & Baime, M. J. (2010). Mindfulness-based stress reduction: Effect on emotional distress in older adults. *Complementary Health Practice Review, 15*(2), 59-64. doi:10.1177/1533210110387687

Zhang, J.-x., Liu, X.-h., Xie, X.-h., Zhao, D., Shan, M.-s., Zhang, X.-l., . . . Cui, H. (2015). Mindfulness-based stress reduction for chronic insomnia in adults older than 75 years: a randomized, controlled, single-blind clinical trial. *Explore, 11*(3), 180-185. doi:10.1016/j.explore.2015.02.005

Zollars, I., Poirier, T. I., & Pailden, J. (2019). Effects of mindfulness meditation on mindfulness, mental well-being, and perceived stress. *Currents in Pharmacy Teaching and Learning, 11*(10), 1022-1028. doi:10.1016/j.cptl.2019.06.005

Chapter 2: Empirical Study

An investigation of the relationship between carer burden and depression and anxiety in older kinship carers

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Abstract

Little is known regarding how kinship carers experience carer burden and its effect on depression and anxiety. This study aimed to explore the relationship between carer burden and depression and anxiety in kinships carers over 55 years of age. Furthermore, this study sought to explore how the psychological resources of self-compassion, dispositional mindfulness and mastery affect the relationship between carer burden and psychological wellbeing. Quantitative data was gathered using online self-report questionnaires. A total of 113 participants completed the study. Results indicated that carer burden was positively associated with depression and anxiety. Through the use of conditional process analysis, both dispositional mindfulness and mastery were found to mediate the relationship between carer burden and depression. In the relationship between carer burden and anxiety, dispositional mindfulness was found to be a mediator, whilst self-compassion was found to moderate the relationship. These results highlight potential protective factors, which may be harnessed to reduce the development of psychological distress in the older kinship carer population. Study limitations and implications for practice are discussed.

Keywords: kinship carer, carer burden, depression, anxiety, self-compassion, mindfulness

1. Introduction

1.1. Kinship Carers

In the UK, where a young person cannot live with their parents, current law and policy gives priority to placement with the young person's extended family, in an arrangement known as kinship care (Kinship, 2021). Extended family care, as opposed to alternative arrangements such as foster care, is reinforced by evidence of equal or better outcomes for young people in kinship care compared with care by a "stranger" (Wellard, 2017). Although some argue the preference for kinship care reflects a development evolving more out of scarcity of alternative care options than a child-centred policy, the positive outcomes of kinship care are well documented. These include fewer disrupted placements than children in foster care, and fewer mental health disorders and behavioural problems (Rock, Michelson, Thomson, & Day, 2015; Winokur, Holtan, & Batchelder, 2014). Kinship care is the most prevalent form of non-parental care in the UK with 31% of children identified as care-experienced in Scotland being looked after formally in kinship care (Scottish Government, 2021). Kinship care arrangements can be "formal", where the local authority responsible for the child assesses and approves carers who will be entitled to financial and emotional support, or "informal", typically resulting from a private arrangement between the child's parent and kinship carer. Due to the nature of informal kinship care, true figures for the overall number of kinship carers in the UK are unavailable and as a result little is known about them from a research standpoint.

A recent survey of 1,651 UK based kinship carers found that 65% of respondents were between 55 and 85 years old, making them older than the majority of parents raising children (Kinship, 2021). These figures are in keeping with previous surveys, which highlight that the largest proportion of kinship carers are over 55 years of age, and are often grandparents of the child they are caring for (Kiraly, 2015). Due to older carers being the most prevalent and research into other older carer groups indicating they have different needs and ways of coping compared to younger counterparts (Koyama et al., 2017), this study chose to focus on older kinship carers.

1.2. Kinship Carers' Wellbeing

With the majority of research focusing on the social, emotional and behavioural outcomes of the young people in kinship care arrangements, the outcomes for the carers themselves are often overlooked. However, research indicates that the wellbeing of the caregiver impacts upon outcomes for the young person. For example, depression among kinship carers has been shown to lead to poorer outcomes for the young person (Garcia et al., 2015) and greater carer stress has been found

to increase placement disruption (Rock et al., 2015). These studies highlight the importance of expanding the understanding of carer wellbeing, in order to assist the carers themselves as well as those they care for.

There are many adverse factors that kinship carers may face which might impact upon their mental wellbeing, including child behavioural difficulties (Winokur, Holtan, & Batchelder, 2018), challenging family dynamics, financial pressures and role changes, among others (Sharda, Sutherby, Cavanaugh, Hughes, & Woodward, 2019). For older kinship carers, taking on the parenting role later in life means that some of these factors, such as financial pressures, may be further exacerbated and factors, such as declining physical health, may also be relevant (Hayslip Jr & Kaminski, 2005). The effects of the current increase in energy and general living costs means financial pressures are further increased, often affecting those from lower incomes the most (Age UK, 2022). As many kinship carers fall into this lower income bracket (Kinship, 2021), the current financial climate may further intensify adverse mental wellbeing. The limited research exploring anxiety and depression in this population reports higher levels of anxiety and depression among kinship carers, compared to non-caregiving peers (Dunne & Kettler, 2008; Kelley, Whitley, Sipe, & Yorker, 2000). It is worth highlighting that these studies did not take place in the UK nor take into account the impact of COVID-19 and the resulting lockdowns. In a recent survey, 63% of UK based kinship carers stated that the lockdown restrictions had a negative impact on their physical and mental health (Kinship, 2021). It is therefore important that current research takes the impact of the COVID-19 pandemic into account.

1.3. Model of Caregiver Stress

Whilst kinship carers as a population clearly experience a range of stressors, and as a collective display poorer mental health outcomes than their non-caregiving peers, there are also important individual differences. Whilst some carers do experience adverse mental health outcomes, others do not, despite facing similar stressors (Elmore, 2014). In an attempt to conceptualise this discrepancy, the stress process model (Lazarus & Folkman, 1984) has been used, which states that stressful events alone do not determine the intensity of the negative outcome. Instead, stress is mediated by an individual's appraisal of the stressor and the coping resources they possess. Pearlin et al. (1990) extended the model to identify risk and protective factors for caregiver wellbeing, and to provide a theoretical framework for carer psychological interventions (Pearlin, Mullan, Semple, & Skaff, 1990). The model specifies several types of risk factors: background and contextual factors (such as age, gender, socioeconomic status and time caring); stressors, perceived burden and psychological

moderators, mediators of stress (such as coping strategies, social support and personality), and the outcomes (such as anxiety and depression).

Although this model is grounded in more than two decades of carer research, it has never been explored in relation to older kinship carers. Increased knowledge regarding factors associated with negative psychological outcomes in kinship carers will aid in identifying those most at risk for developing anxiety and depression, and lead to insight regarding potential psychological interventions.

1.4. Carer Burden

Carer burden is a phrase used to define carers' perception of changes in their behaviour and life as a result of their caring role (Bowers & Myers, 1999; Zarit, Reever, & Bach-Peterson, 1980). In keeping with the stress process model, research across a variety of populations has found higher levels of carer burden predict increased levels of anxiety and depression (del-Pino-Casado, Priego-Cubero, López-Martínez, & Orgeta, 2021; Geng et al., 2018). There is evidence to suggest the same relationship exists within the kinship carer population, where levels of caregiver burden were found to positively correlate with levels of depression (Force, Botsford, Pisano, & Holbert, 2000).

Carer burden has been shown to be associated with feelings of guilt, frustration and loss of control (Springate & Tremont, 2014). Therefore, when considering the stress process model, it could be suggested that these feelings may be linked to mechanisms through which increased carer burden leads to greater psychological distress. Such factors linked to these feelings include self-compassion, dispositional mindfulness and mastery. These factors have been explored within the stress process model as factors which influence the impact of carer burden on both depression and anxiety.

1.5. Self-compassion

Self-compassion, a positive and caring attitude toward oneself in potentially threatening situations, has been identified as an important correlate of coping in stressful situations (Ewert, Vater, & Schröder-Abé, 2021). Research indicates that individuals with higher levels of self-compassion may encounter less stressors. Authors found that by engaging in protective self-care behaviours, individuals may appraise stressors differently, experience different physiological responses to stress, and deploy different strategies when faced with stress (Finlay-Jones, 2017). Thus, in keeping with the stress process model, high levels of self-compassion can be seen as a personal resource which may help someone to take the perspective of shared human experience and therefore appraise stressors and personal weaknesses as less threatening (Neff, Hsieh, & Dejitterat, 2005).

There is a large body of research indicating associations between higher levels of self-compassion and decreased depression, anxiety and stress across age groups (Hughes, Brown, Campbell, Dandy, & Cherry, 2021). Furthermore, self-compassion has been identified as a mechanism of change in psychological interventions, with Compassion Focused Therapy (Gilbert, 2005) and Acceptance and Commitment Therapy (Hayes, Strosahl, & Wilson, 2009) found to be effective in reducing depression and anxiety in a variety of clinical and non-clinical populations (Wilson, Mackintosh, Power, & Chan, 2019).

There is some evidence that self-compassion can moderate the relationship between carer burden and depression (Hsieh et al., 2019; Xu, Zhang, & Wang, 2020), supporting the hypothesis that self-compassion can act as a protective factor against the impact of carer burden on the mental health of caregivers. The moderating role of self-compassion has never been explored in the kinship carer population, nor has it been investigated as a moderator in the relationship between carer burden and anxiety. If self-compassion is seen as a personal resource, as posited by the stress process model, then it could be hypothesised that self-compassion acts as a buffer in models concerning both depression and anxiety. This is due to the mechanisms through which self-compassion is thought to impact on psychological wellbeing, which is through responding to threat with soothing emotional regulation abilities (Gilbert, 2009).

1.6. Mindfulness

Mindfulness can be defined as the ability to attend in a non-judgemental way to one's own physical and mental state during everyday experiences (Kabat-Zinn, 2003). '*Dispositional mindfulness'* is regarded as an inherent, yet modifiable trait, where all individuals have the varying ability to attend to and be aware of what is happening in the present moment (Brown & Ryan, 2003). Mindfulness, can be utilised as a psychological resource within the stress process model as it is a facet of adaptive coping used to deal with carer stress (Hicks et al., 2019). Higher levels of dispositional mindfulness have been associated with increased psychological health across a range of measures. This relationship is thought to be down to mechanisms of adaptive cognitive processes, where dispositional mindfulness is positively linked to decreased rumination and increased emotional processing (Tomlinson, Yousaf, Vittersø, & Jones, 2018). Psychological therapies with mindfulness at their core, such as mindfulness based stress reduction and mindfulness-based cognitive therapy, have been found to be effective in improving psychological well-being, reducing stress, burden and depression in carers (Bazzano et al., 2015; Li, Yuan, & Zhang, 2016).

Dispositional mindfulness has been shown to have a protective role against carer burden and psychological health in carers of individuals with physical health problems (Hsieh et al., 2019;

Pagnini, Phillips, Bosma, Reece, & Langer, 2016). Research indicates that greater levels of dispositional mindfulness buffers or mediates the effect of carer stress on measures of anxiety and depression in carers of individuals with Parkinson's disease (Dixon & Overall, 2016; Hicks et al., 2019), although this has not been explored in a population of older kinship carers.

1.7. Mastery

Pearlin et al. (1990) identified mastery, belief in the ability to control one's environment and life circumstances, as a psychological mediator in the stress process model (Pearlin & Schooler, 1978). The role of being a kinship carer requires adaptations by the individual to changing environments, such as taking on the parental role and facing unexpected financial pressures, resulting in the potential to feel a loss of control (Dunne & Kettler, 2008). Therefore, due to the stressful and ever-changing nature of kinship caring, kinship carers may be at greater risk of low levels of mastery. Research has shown that an individual's ability to feel in control, or their sense of mastery, is related to how they experience stress, carer burden, anxiety and depression (Chan, Glass, Chua, Ali, & Lim, 2018). It is thought that those with higher levels of mastery make better links between their own actions and outcomes, leading to better adaptation when faced with stress (Ben-Zur, 2002). Therefore, exploring mastery in kinship carers is important, as it could highlight a potential target for psychological intervention by helping people make these links.

Following the conceptualisation of mastery as a mediator within the stress process model, a number of studies assessed its effects in the caregiving process and demonstrated its effects (Cairney & Krause, 2008; Mausbach et al., 2012). Research indicates mastery is negatively associated with depression, with mastery mediating the relationship between carer burden and psychological outcomes amongst an older caregiving population (Khalaila & Cohen, 2016).

1.8. Aims of Research

There is limited quantitative research on the mental wellbeing of older kinship carers, though existing studies report higher levels of anxiety and depression in kinship carers compared to their peers. The aim of this research is to develop a greater understanding of the mental wellbeing of this population, by examining the impact of carer burden on levels of anxiety and depression. We aim to use the stress process model in this study to examine how kinship carers' internal resources (self-compassion, dispositional mindfulness and mastery) influence the relationship between carer burden and psychological wellbeing. This will give further understanding as to where potential interventions to reduce anxiety and depression should be targeted in this population.

The objectives were to identify whether:

1. Carer burden predicts anxiety and depression in older kinship carers.
2. Dispositional mindfulness and mastery mediate the relationship between carer burden and anxiety and depression.
3. Self-compassion moderates the relationship between carer burden and anxiety and depression.

2. Method

2.1. Design

A cross sectional survey design was implemented using quantitative variables measured via self-report questionnaires. Ethical approval was given by the University of Edinburgh, School of Health in Social Science committee (reference: CLIN830) to conduct this study (see Appendix E).

2.2. Participants

Participants self-identified as eligible to participate. Kinship carers over the age of 55 years could participate if they provided care to one or more young person aged 0-21 years and were fluent in English. Exclusion criteria included currently suffering from a cognitive deficit or currently suffering from an unstable mental health condition.

2.3. Procedure

Participants were invited to take part in the study between April and November 2021. Recruitment consisted of a convenience sampling approach, whereby the study was advertised through social media and emails to carer support organisations and kinship peer support groups. Participants completed the study online, via the Qualtrics website, which contained all elements of the study including the participant information sheet, consent form, main questionnaire and debrief information (see Appendix F- M). The questionnaire included questions relating to demographic information, as well as standardised questionnaires addressing anxiety, depression and stress, carer burden, self-compassion, mindfulness and mastery.

As an incentive for participation, participants were offered the chance to be entered into a prize draw to win one of four £25 Amazon gift cards.

2.4. Measures

2.4.1. Depression Anxiety Stress Scale- short version (DASS-21; Lovibond, 1995)

The DASS-21 is comprised of 21 self-report items measuring three separate constructs of psychological distress: depression, anxiety and stress. Higher scores indicate higher levels of distress. Normal levels of depression, anxiety and stress are reported at 9, 7 and 14 respectively. The DASS-21

has been shown to display good internal consistency across all subscales (α= 0.82- 0.90; Henry & Crawford, 2005) . Only the anxiety and depression subscales were used in the present study. Cronbach alpha values for the present sample were 0.90 for depression and 0.79 for anxiety. The DASS-21 shows strong convergent validity to measures of similar constructs (i.e., Beck Depression Inventory, Beck Anxiety Inventory and Penn State Worry Questionnaire) in older adults, whilst reducing the administration burden (Gloster et al., 2008).

2.4.2. Zarit Burden Interview- short form (ZBI-S; Bédard et al., 2001)

The ZBI-S is a 12-item self- report questionnaire measuring carer burden. The short form was developed to reduce the assessment burden and correlates excellently with the original questionnaire (r= 0.92- 0.97), displaying good validity and reliability (α= 0.92) (Bédard et al., 2001). In the current study, internal consistency was strong (α= 0.91). Higher scores indicate higher levels of burden, with score of 13 suggested as the threshold indicative of carer burden (Gratão et al., 2019). Versions of the original ZBI have been used with a variety of caregiving populations, including grandparent caregivers (Conway, Boeckel, Shuster, & Wages, 2010).

2.4.3. Self-Compassion Scale- short form (SCS-SF; Raes, Pommier, Neff, & Van Gucht, 2011)

The SCS-SF consists of 12 self-report items and serves as an economical alternative to the original Self-Compassion Scale (Neff, 2003). Higher scores indicate higher levels of self-compassion with a score of between 1.0- 2.5 indicating low levels, 2.5- 3.5 suggesting moderate, and 3.5- 5.0 indicating high levels (Neff, 2003). Total scores on the SCS-SF have been found to correlate highly (r= 0.98) with the longer version. Furthermore, it has been shown to be comparably reliable and have the same factorial structure as the original scale. The SCS-SF has good internal consistency (α> 0.86), with a test-retest reliability of 0.71. In the current study, internal consistency was 0.82.

2.4.4. Mindful Attention Awareness Scale (MAAS; Brown & Ryan, 2003)

The MAAS is a 15-item self-report questionnaire which measures dispositional mindfulness. Higher scores on this scale indicate higher levels of mindfulness. The scale shows good internal consistency (α= 0.82- 0.87) with a test-retest reliability of 0.83 (Brown & Ryan, 2003). The internal consistency was found to be excellent (α= 0.94), in the present study.

2.4.5. Pearlin Global Mastery Scale (Pearlin & Schooler, 1978)

The Pearlin Global Mastery Scale is a 7-item self-report scale used to measure mastery. A higher score on this scale indicates a greater level of mastery. This scale has been widely used within caregiving populations, and has a good internal consistency (α= 0.88; Bibou-Nakou, Dikaiou, & Bairactaris, 1997). In the current study, internal consistency was found to be 0.85.

2.5. Sample Size

Power analysis was conducted *a priori* to estimate the required sample size. From a calculation using G*Power 3.1 it was estimated that a minimum sample of 85 was required to achieve sufficient power ($\pi = 0.80$) to detect a medium effect size with four predictors (carer burden, self-compassion, mindfulness and mastery) in a regression analysis (Faul, Erdfelder, Lang, & Buchner, 2007). Green's rule of thumb was also considered which states that $N > 104 + m$, where m is the number of predictors (Green, 1991). According to this rule, a minimum sample size of 108 would be needed to detect a medium effect.

For conditional process analysis, it is recommended that a minimum of 77 participants are sufficient to detect medium-sized effects in a simple mediation model (Fritz & MacKinnon, 2007). As such, the current sample size was considered adequately powered.

2.6. Analysis

The analysis was carried out using IBM SPSS version 25. The PROCESS (version 4.0) syntax (Hayes, 2017) was utilised to conduct the conditional process analysis.

Descriptive and comparative analyses were undertaken to provide information about the sample. Differences between demographic groups and sample characteristics were explored to identify potential covariates to control for in subsequent analyses. Analysis of variance (ANOVA) was used to examine group mean differences of categorical variables on dependent variables. Pearson's correlation coefficient was used to explore any significant relationships between continuous demographic variables and dependent variables.

Correlational analysis (Pearson's *r*) was used to identify the relationship between key variables. These key variables, decided apriori and informed by the stress process model, were carer burden, anxiety, depression, self-compassion, dispositional mindfulness and mastery.

Forced entry multiple linear regression analysis was used to develop models of the factors that predict anxiety and depression within the kinship carer population. The assumptions for regression analyses were met, including checks for heteroscedasticity, normality of residuals and linearity (Field, 2005). Each model was tested for outliers as well as confirming that the data met the assumption of independent errors through the Durbin-Watson test (Field, 2013).

PROCESS Model 4 was used to conduct simple mediation analyses using dispositional mindfulness and mastery as potential mediators in the relationship between carer burden and depression and anxiety. Following this, conditional process analysis, using PROCESS Model 5, was used to explore

the specific roles of, and relationships between the variables, and to determine the role of self-compassion as a potential moderator. Separate models were run for anxiety and depression.

3. Results

123 participants from the UK were recruited. Of the 123 respondents, 11 completed only the demographic questions and were therefore excluded from all analysis. Hence, a total of 112 completed the full set of questionnaires and were therefore included in the study.

3.1. Data Screening

Missing values were identified in the quantitative questionnaires and were found to be minimal, with no more than 1.8% of missing values found for any item. Little's Missing Completely at Random Test (MCAR; Little & Rubin, 1989) was conducted to examine the pattern of missing values and this was found to be non-significant (χ^2 = 1634.96, df (1633), p= 0.482). Missing values in the DASS-21 were replaced according to the developer's instructions, using case-mean data substitution. The case-mean data substitution method was also used to impute missing values from the ZBI-12, SCS-SF, MAAS and PMS (Tagliabue & Donato, 2015).

The assumptions for parametric analysis were met. To assess distribution of the data, the skewness and kurtosis of outcome measures were examined. Values were all within the guidance range of -2 to +2 for skewness and -7 to +7 for kurtosis, indicating that the data is not substantially skewed nor too peaked (Hair et al., 2017). The assumption of normality was checked by examining p-plots, with normal p-plots confirmed. All variance inflation factor (VIF) values were under 3 and tolerance values over 0.2 indicating the absence of multicollinearity.

Participant Characteristics

Participants had an average age of 61.64 years (SD= 5.25) and had been a kinship carer for an average of 5.44 years (SD= 3.64). The young people looked after by participants had an average age of 9.89 years (SD= 4.14). Participants' full demographic information is presented in Table 1.

Results, according to the scoring guidelines of the measures used, suggest that the current sample reported on average: moderate levels of depression, mild levels of anxiety, moderate to high levels of burden, moderate levels of self-compassion and below average levels of dispositional mindfulness. There are no norms provided for the Pearlin Mastery Scale, however the mean mastery scores in this sample are similar to samples of older adult caregivers (e.g., McAuliffe, Ong, & Kinsella, 2020). See Table 2 for the sample's full descriptive statistics.

Table 1. Characteristics of the sample

VARIABLE		*N*	%	MEAN (SD)	RANGE
AGE		112		61.64 (5.25)	55-75
GENDER					
	Female	106	94.6		
	Male	6	5.4		
COUNTRY OF RESIDENCE					
	Scotland	37	33.0		
	England	70	62.5		
	Wales	3	2.7		
	Other	2	1.8		
ETHNICITY					
	White	111	99.1		
	Mixed or multiple ethnic group	1	0.9		
HIGHEST LEVEL OF EDUCATION					
	Primary School	2	1.8		
	Standard Grades, GCSEs or equivalent	44	39.3		
	Scottish Highers, A Levels or equivalent	26	23.2		
	Undergraduate Degree	18	16.1		
	Postgraduate Degree	21	18.8		
	Prefer not to say	1	0.9		
ANNUAL HOUSEHOLD INCOME					
	Less than £10,000	9	8.0		
	£10,000 to £19,999	33	29.5		
	£20,000 to £29,999	35	31.3		
	£30,000 to £39,999	19	17.0		
	£40,000 to £49.999	5	4.5		
	More than £50,000	10	8.9		
	Prefer not to say	1	0.9		
TYPE OF CAREGIVER					
	Formal kinship carer	100	89.3		
	Informal kinship carer	11	9.8		
	Prefer not to say	1	0.9		
TIME AS A KINSHIP CARER (YEARS)		112		5.44 (3.64)	0.8- 15.7
RELATIONSHIP TO CHILD					
	Grandparent	101	90.2		
	Great aunt or uncle	4	3.6		
	Other	7	6.2		
NUMBER OF CHILDREN CARED FOR					
	1	79	70.5		
	2	20	17.9		
	3	12	10.7		
	4	1	0.9		
AGE OF CHILDREN CARED FOR (YEARS)		112		9.89 (4.14)	0.3- 21
HELP FROM ADDITIONAL CARERS					
	Only carer	46	41.1		
	Shares duties with others	66	58.9		
EMPLOYMENT STATUS					
	Employed	50	41.7		
	Unemployed/ retired	70	58.3		
CURRENTLY SEEKING PROFESSIONAL HELP FOR MENTAL HEALTH					
	Yes	10	8.9		
	No	100	89.3		
	Prefer not to say	2	1.8		
HAVE YOUR ANSWERS BEEN INFLUENCED BY COVID PANDEMIC?					
	No	63	56.3		
	Yes- been impacted for the worst	39	34.8		
	Yes- been impacted for the better	6	5.4		
	Missing data	4	3.6		

Table 2. Descriptive data on dependent and independent variables

MEASURE	SCALE RANGE	MIN	MAX	MEAN	SD
DASS-21 DEPRESSION	0- 42	0.00	42.00	13.27	9.19
DASS-21 ANXIETY	0- 42	0.00	34	7.75	6.76
ZBI-S	0- 48	1.00	43.00	18.26	11.42
SCS-SF	1- 5	1.42	4.75	3.03	0.73
MAAS	1- 6	1.33	6.00	3.62	1.13
PMS	1- 28	9.00	28.00	17.49	4.54

DASS-21 Depression Anxiety Stress Scale; ZBI-S Zarit Burden Interview- short form; SCS-SF Self-compassion Scale- short form; MAAS Mindful Attention Awareness Scale; PMS Pearlin Mastery Scale

3.3. Covariates

Demographic variables examined included age, gender, level of education, annual household income, employment status, time as a kinship carer, type of kinship carer, age of children cared for and number of children cared for. Significant differences on dependent variables were also explored between participants who stated that their answers to the questionnaires had been impacted negatively by the COVID pandemic, positively by the COVID pandemic and those who stated that their answers had not been influenced at all. As no significant differences were found, none of these demographic factors were deemed covariates and therefore were not controlled for in subsequent analyses.

3.4. Correlations

Pearson's correlations were conducted to examine the relationships between the variables (see Table 3). All variables were significantly correlated at the level of $p \leq 0.01$. Higher levels of carer burden were correlated with greater levels of anxiety and depression. Greater levels of self-compassion, dispositional mindfulness and mastery were correlated with lower levels of anxiety and depression.

Table 3. Bivariate correlations between variables

VARIABLES	1	2	3	4	5	6
1. DEPRESSION (DASS-21 D)	1					
2. ANXIETY (DASS-21 A)	0.65*	1				
3.CARER BURDEN (ZBI-S)	0.58*	0.49*	1			
4. SELF-COMPASSION (SCS-SF)	-0.52*	-0.49*	-0.51*	1		
5. MINDFULNESS (MAAS)	-0.56*	-0.61*	-0.60*	0.63*	1	
6. MASTERY (PMS)	-0.50*	-0.34*	-0.47*	0.56*	0.51*	1

*$p \leq 0.05$

3.5. Regression

3.5.1. Prediction of Depression

See Table 4 for the multiple regression analysis testing the predictive power of variables on depression. The final model predicted 42.4% of the variance (Adj R^2= 0.424), which was highly significant ($F_{(4,107)}$ = 21.422, p< 0.001). While carer burden contributed significantly to the model (B= 0.248, p< 0.001), self-compassion (b= -0.160, p= 0.133), dispositional mindfulness (b= -1.538, p= 0.071) and mastery (b= -0.337, p= 0.071) did not.

Table 4. Multiple regression analysis of depression

VARIABLE	BETA COEFFICIENT	T	*P*-VALUE	R^2	ADJUSTED R^2
				0.445	0.424
CARER BURDEN (ZBI)	0.248	3.307	0.001*		
SELF-COMPASSION (SCS-SF)	-0.160	-1.515	0.133		
DISPOSITIONAL MINDFULNESS (MAAS)	-1.538	-1.826	0.071		
MASTERY (PMS)	-0.337	-1.825	0.071		

*p<0.05

3.5.2. Prediction of Anxiety

See Table 5 for the multiple regression analysis on anxiety; the final model predicted 38.2% of the variance (Adj R^2= 0.382), which was highly significant ($F_{(4,107)}$ = 18.136, p< 0.001). While dispositional mindfulness contributed significantly to the model (b= -2.562, p< 0.000), carer burden (b= 0.106, p= 0.068), self-compassion (b= -0.119, p= 0.142) and mastery (b= 0.074, p= 0.603) did not.

Table 5. Multiple regression analysis of anxiety

VARIABLE	BETA COEFFICIENT	T	*P*-VALUE	R^2	ADJUSTED R^2
				0.404	0.382
CARER BURDEN (ZBI)	0.106	1.844	0.068		
SELF-COMPASSION (SCS-SF)	-0.119	-1.480	0.142		
DISPOSITIONAL MINDFULNESS (MAAS)	-2.562	-3.990	0.000*		
MASTERY (PMS)	0.074	0.522	0.603		

*p<0.05

3.6. Mediation Analysis

3.6.1. Depression

PROCESS Model 4 was used to test the hypothesis that dispositional mindfulness and mastery mediate the relationship between carer burden and depression. The beta coefficients reported are unstandardised and all boot-strapped confidence intervals are of 5000 resamples. Carer burden had

a direct effect on depression (*b*= 0.264, *SE = 0.075, p*< 0.001), and this remained significant when controlling for the mediators (*b*= 0.464, *SE =0.063, p*< 0.001). Approximately 33.3% of the variance (Adj R^2 = 0.333) was accounted for by the predictors. There was a significant indirect effect of both dispositional mindfulness (*b*= 0.120, 95% LLCI= 0.041, ULCI= 0.221) and mastery (*b*= 0.080, 95% LLCI= 0.022, ULCI= 0.147), supporting the hypothesis that they act as mediators in the relationship between carer burden and depression (see Figure 1).

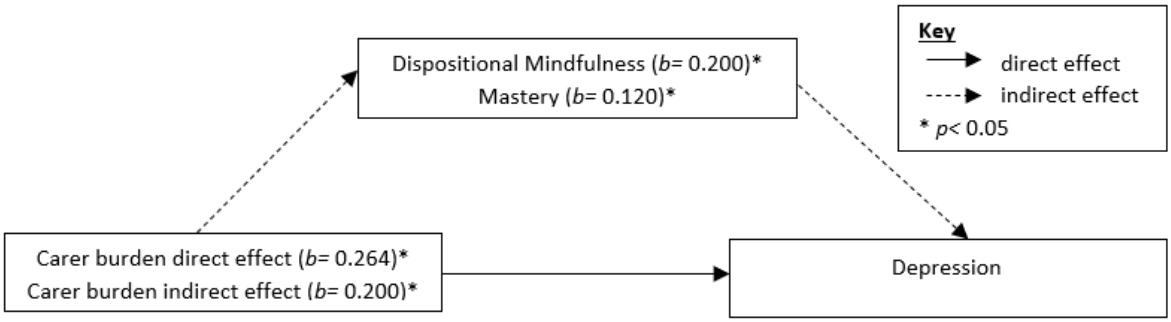

Figure 1. Mediation model of relationship between carer burden and depression

3.6.2. Anxiety

The mediation was repeated using anxiety as the Y variable, to test the hypothesis that dispositional mindfulness and mastery mediate the relationship between carer burden and anxiety. Carer burden had a direct effect on anxiety (*b*= 0.117, *SE = 0.057, p*= 0.042), and this relationship was strengthened after controlling for the mediators (*b*= 0.289, *SE = 0.049, p*< 0.001). Approximately 23.8% of the variance (Adj R^2= 0.238) was accounted for by the predictors. There was a significant indirect effect of dispositional mindfulness (*b*= 0.173, 95% LLCI= 0.105, ULCI= 0.251) but not mastery on anxiety, meaning that whilst mindfulness was found to mediate the relationship between carer burden and anxiety, mastery did not (see Figure 2).

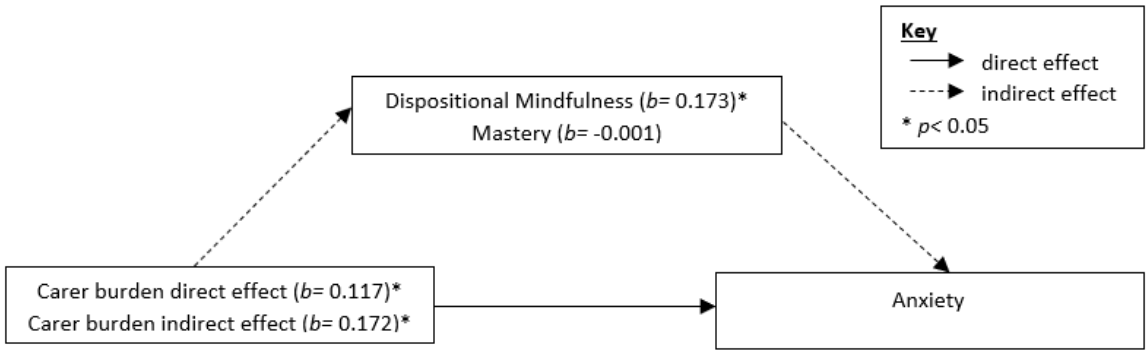

Figure 2. Mediation model of relationship between carer burden and anxiety

3.7. Conditional Process Analysis

The correlations and regressions detailed above suggest that carer burden significantly predicts depression and is positively associated with anxiety in kinship carers, thus addressing objective 1. The use of simple mediation addressed objective 2, suggesting that dispositional mindfulness and mastery significantly mediate the relationship between carer burden and depression, whilst only mindfulness acts as a moderator in the relationship between carer burden and anxiety in this population. Conditional process analysis, using PROCESS Model 5, was used to add to these findings and address objective 3, whether self-compassion moderates the relationship between carer burden and depression and anxiety. It was also used to identify whether different levels of self-compassion influence these relationships.

3.7.1. Depression

The model used to explore the outcome of depression is shown in Figure 3. It accounted for 43% of the variance in depression which was significant (R^2= 0.430, $F_{(4,107)}$= 20.18, p< 0.001). Self-compassion was not found to be a significant moderator (b= -0.005, p= 0.485) in the relationship between carer burden and depression. However, levels of self compassion do appear to influence the strength of the relationship between carer burden and depression, with higher levels (+1 SD) weakening the direct effect of carer burden on depression.

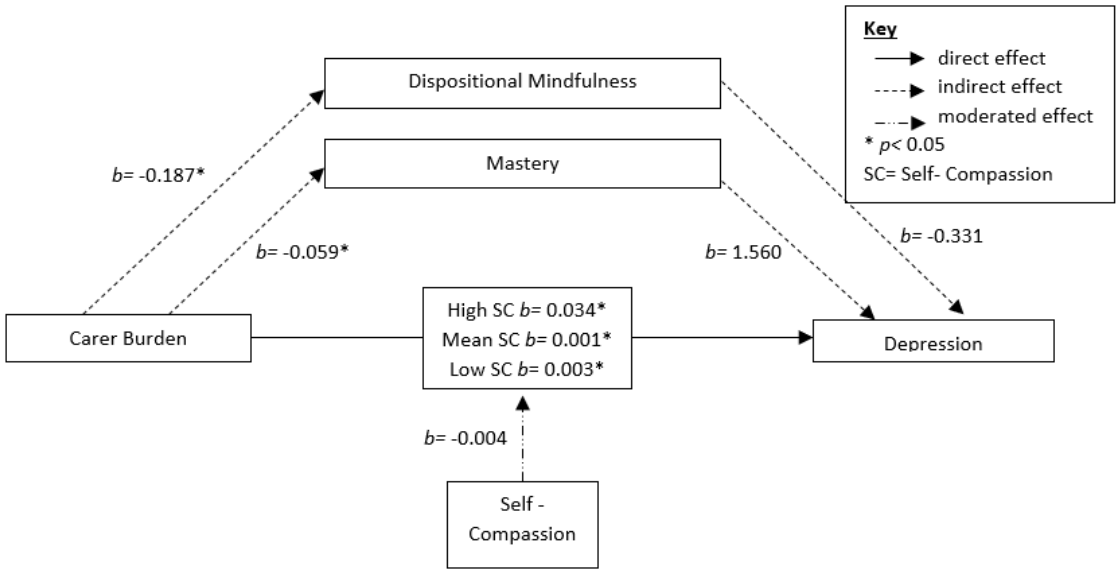

Figure 3. Conditional process analysis model of relationship between carer burden and depression

3.7.2. Anxiety

The analysis was repeated, using anxiety as the outcome variable, shown in Figure 4. This model accounted for 44.1% of the variance (R^2= 0.441, $F_{(5,106)}$= 60.89, p< 0.001). Self-compassion was found to significantly moderate the influence of carer burden (b= -0.013, p= 0.009*)*. At mean and high levels (+1 SD) of self-compassion, carer burden no longer significantly predicted anxiety. This suggests that self-compassion buffers the effects of carer burden on anxiety.

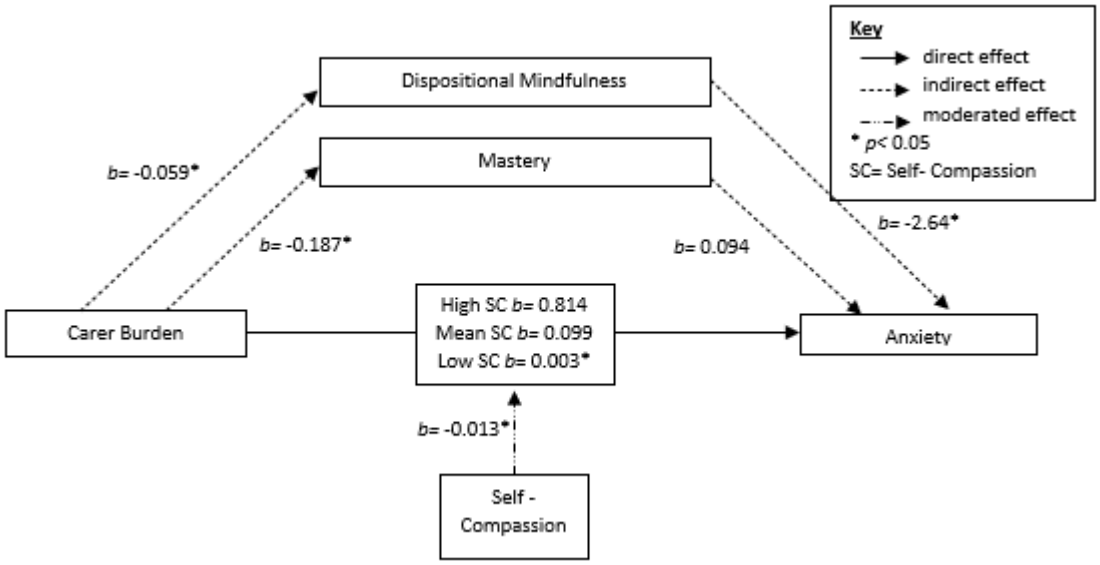

Figure 4. Conditional process analysis of relationship between carer burden and anxiety

4. Discussion

This study aimed to explore the impact of carer burden on depression and anxiety in a sample of older kinship carers. We applied the stress process model (Lazarus & Folkman, 1984; Pearlin et al., 1990) to examine how self-compassion, dispositional mindfulness and mastery may influence the relationship between carer burden and anxiety and depression. Existing research has demonstrated that self-compassion, dispositional mindfulness and mastery can all act as protective factors in the relationship between carer burden and distress (Hicks et al., 2019; Hsieh et al., 2019; Khalaila & Cohen, 2016). However, although these factors had been explored with various caregiving populations, they had not been explored in a kinship carer population. Current statistics reporting the majority of kinship carers to be over 55 years, coupled with the knowledge that this age group is less likely than younger adults to have their mental health difficulties recognised or treated, resulted in this study recruiting older kinship carers. Understanding factors that may protect kinship carers from anxiety and depression is important, not just for the carers themselves but for the young

people they look after. Therefore, this study aimed to highlight older kinship carers' psychological needs to inform potential systemic support when considering young people in kinship care.

The sample recruited in this study was predominantly female (94.6%), grandparent (90.2%) kinship carers, who share the caring responsibility with someone else (58.9%) in a formal caring arrangement (89.3%). This demographic data is similar to previous research in this population (Dunne & Kettler, 2008; Harding, Murray, Shakespeare-Finch, & Frey, 2020), suggesting that this sample was representative of kinship carers who take part in research. The majority of participants reported that their household income was less than the national average of £31,000 (ONS, 2021). This is also in line with current kinship carer statistics, indicating that the two thirds of kinship carers worry about their financial situation and feel they cannot financially meet the needs of the young people they look after (Kinship, 2021). This sample was ethnically homogeneous with 99.1% of the sample reporting White ethnicity. This differs from recent survey findings indicating that 65% of the kinship carer population are from a White background (Kinship, 2021) and previous census data indicating that up to 32% of young people in kinship care were from non-White backgrounds (Selwyn & Nandy, 2012). It is understood that individuals from ethnic minority groups may be less likely to take part in psychological research (Sheridan et al., 2020). Furthermore, it may be that kinship carers from ethnic minority groups may be less likely to identify as kinship carers (Kinship, 2021) and therefore less likely to be involved with formal support groups through which this study recruited.

Moderate to high levels of carer burden were found in this study, highlighting the pressure and strain felt by older kinship carers. This is in line with levels of carer burden experienced by other older caregiving groups, including carers of individuals with Parkinson's disease (Hagell, Alvariza, Westergren, & Årestedt, 2017) and dementia (Branger, O'Connell, & Morgan, 2016). Moderate levels of depression and low levels of anxiety were also reported by older kinship carers in this study. Again, this is similar to previous findings on the psychological health of kinship carers (Dunne & Kettler, 2008), where researchers found significantly higher levels of depression and anxiety compared to non-caregiving peers. The findings of Dunne and Kettler (2008) highlight that although levels of anxiety within the present study are classed as low according to the DASS-21 norms, these results are likely to be higher than a non-caregiving comparison group.

This study sought to identify whether carer burden predicted anxiety and depression in older kinship carers. Correlations were initially performed to explore the basic relationships between variables. As predicted, carer burden was significantly correlated with both depression and anxiety. Regression analyses subsequently confirmed carer burden to be a significant predictor of depression. Interestingly, carer burden was not a significant predictor of anxiety, instead dispositional

mindfulness was shown to be significant in this model. It is possible that despite having predictive value, the strength of the relationship between carer burden and anxiety was not as strong as the relationship between dispositional mindfulness, self-compassion, mastery and anxiety. Therefore, when explored alongside these factors in a regression, carer burden did not reach statistical significance.

A further objective of the present study was to identify how individual differences can impact on the relationship between carer burden and psychological wellbeing in older kinship carers. This study used the stress process model to inform the hypotheses that dispositional mindfulness and mastery would mediate, and self-compassion moderate the relationship between carer burden and depression and anxiety. Correlations suggest that individuals with higher levels of dispositional mindfulness, mastery and self-compassion are significantly less likely to report symptoms of depression and anxiety. In this study dispositional mindfulness was found to be a significant mediator for the relationship between both carer burden and depression and carer burden and anxiety, as reported by others (Dixon & Overall, 2016). This means that an individual's level of dispositional mindfulness significantly influences the impact that carer burden has on psychological wellbeing, with increased dispositional mindfulness resulting in lower impact. This may be due to more mindful individuals being able to focus on the present moment as opposed to ruminating on their stress, which is more likely to lead to the development and maintenance of poor psychological wellbeing (Tomlinson et al., 2018).

Although mastery was found to be a significant mediator in the relationship between carer burden and depression, this was not the case in the relationship between carer burden and anxiety. However, correlations indicate that mastery is significantly negatively associated with anxiety and it added to a proportion of the variance in the regression model, suggesting that a relationship does exist. Much of the existing research does indeed focus on the effect of mastery on depression (Khalaila & Cohen, 2016) and similar results to those found in this study have been reported elsewhere (Chan et al., 2018). The results suggest that individuals who have higher mastery, and hence feel in greater control of their actions, are able to cope more adaptively with carer burden, thus protecting them from symptoms of depression. The reason why the same effect was not discovered in regard to anxiety in this study is unclear, however it may be due to the different cognitive processes that play a role in the development and maintenance of anxiety compared to depression (Mathews, 1986). Further research could investigate the cognitive processes involved in mastery within this population.

The final objective of the present study was to determine the potential role of self-compassion as a moderator in the relationship between carer burden and depression and anxiety. Through the use of conditional process analysis, this study was able to explore this objective whilst examining fit of all variables on depression and anxiety. Self-compassion was found to significantly moderate the relationship between carer burden and anxiety but not carer burden and depression. This means that in this sample of older kinship carers, higher levels of self-compassion significantly weakened the effect of carer burden on anxiety. This is a novel finding, as self-compassion has not been explored as a moderator in this way before. This finding supports the theory posited by the stress-process model that self-compassion can be seen as a personal resource used to buffer the impact of stress on emotional wellbeing. The finding contributes further to the evidence base of the impact of self-compassion on psychological wellbeing, namely that higher self-compassion appears to facilitate better emotion regulation skills, reducing distress (Gilbert, 2009).

The same significant effect was not found in the depression model, however higher levels of self compassion were seen to weaken the direct influence of carer burden on depression. This is not consistent with previous research which found self-compassion to be a significant moderator of carer burden on depression in caregivers of individuals with cancer (Hsieh et al., 2019; Xu et al., 2020). This difference in findings could be explained by the different stresses faced by older kinship carers compared with caregivers of individuals with cancer. Furthermore, both of these studies used different measures to examine depression than the DASS-21 used in the present study, which may have contributed to differences in the findings.

4.1. Implications for Clinical Practice

The high levels of carer burden experienced by this population and the finding that carer burden predicts anxiety and depression are of key significance. This finding provides evidence that carer burden should be recognised within older kinship carers and measures taken to address it in order to improve their emotional wellbeing.

Furthermore, the findings that dispositional mindfulness, mastery and self-compassion all positively influence and potentially buffer the effects of caregiver burden on psychological wellbeing in this population are significant for practice. These factors are all potential modifiable targets for psychological intervention. Compassion Focused Therapy (CFT) would be one such intervention as it aims to increase both self-compassion and mindfulness (Gilbert, 2009). Acceptance and Commitment Therapy (ACT) could also increase mindfulness and mastery, as it aims to increase awareness of cognitive appraisals and helps individuals to relate to themselves with increased awareness and compassion in times of stress (Hayes, Strosahl, & Wilson, 2012). Such interventions

have been shown to be effective with caregivers of children with neurodevelopmental disabilities (Magnacca, Thomson, & Marcinkiewicz, 2021) as well as older caregivers of people with dementia (Fauth, Novak, & Levin, 2021).

Overall, the stress process model appeared to be a good theoretical lens to explain how the factors in the present study relate to each other. This is an important finding as it suggests that psychological factors that influence how carer burden impacts on psychological wellbeing in the older kinship carer population are similar to those which have been explored in other caregiving populations, such as those who care for individuals with physical health conditions or caregivers of people with dementia. Kinship carers are often seen as an "invisible" population compared with other caregiving populations (Selwyn & Nandy, 2012); however, the results of this study indicate similarities and therefore provide further evidence for the recognition and support of kinship carers.

4.2. Limitations, Strengths and Further Research

This study was cross-sectional, and as such accounted for a single point in time which has its consequences. For example, it is likely that an individual's level of burden, self-compassion, dispositional mindfulness and mastery fluctuate, which the current design does not account for. Future research could use a longitudinal or cohort design to provide further insight into how the factors measured in this study influence depression and anxiety. The use of a control condition would also add the benefit of comparing kinship carers to non-caregiving peers. Additionally, qualitative research could be conducted to provide depth to the present study by investigating kinship carers' experience of coping with carer burden.

The method of recruitment means that highly motivated individuals are more likely to complete the study. Individuals who are experiencing high levels of carer burden, depression or anxiety may be less likely to complete the study. Furthermore, this study's exclusion criteria prevented kinship carers with severe unstable mental health conditions from participating. Thus, the results may be an underrepresentation of the distress experienced by the kinship carer population.

As discussed above, although the sample included in this study was representative of the older kinship carer population in some ways, in other ways it was not. For example, there was very limited ethnic diversity of participants and the majority of participants were formal kinship carers. This lack of diversity may have been due to recruitment using kinship charities and support groups, which individuals from ethnic minorities or informal kinship carers may be less likely to be members of. Future research could address this by using wider recruitment methods and targeted sampling. Additionally, this sample had an average range of 61.64 years with the oldest participant reported to be 75 years. Therefore, this sample does not represent the oldest old kinship carers and future

research should ensure that the oldest old are included to fully capture the effects of age on the caregiving process.

This study used the stress process model as a theoretical basis and investigated specific psychological mediators of stress. However, it did not explore the impact of other mediators such as social support, specific coping strategies (e.g., exercise) or facets of personality, as detailed in the model. The rationale behind the decision to not include further variables was to limit the response burden placed on participants. This was especially relevant as recruitment took place during the COVID-19 pandemic, where caregivers may have been under increased stress due to added demands placed on them as a consequence of lockdown (e.g., home-schooling). However, by not considering these factors it is hard to determine how the stress process model fits fully within this population.

Further confounding factors which were not measured in this study are those concerning the young person or people looked after by the kinship carer. For example, the attachment relationship the kinship carer has with the young person they care for is thought to impact upon carer wellbeing (Pasalich, Moretti, Hassall, & Curcio, 2021). Future research in this population could consider the impact of attachment as a further mediator of stress.

Lastly, it is worth highlighting that the models tested within this study were based on *a priori* hypothesis. It is likely that the factors explored in this study relate to each other in ways not tested within this research, which may have implications for the overall findings.

Strengths of this study include gaining an adequate sample size and using valid and reliable psychological measures to investigate a novel area of research. Furthermore, this study took place during the COVID-19 pandemic, which is reported to have had a negative impact on individuals' psychological wellbeing (Pierce et al., 2020). This study accounted for this impact by asking participants to report whether the pandemic had affected their response to the study. 56.3% of participants stated their results were unaffected by the impacts of COVID-19, 34.8% reported their responses had been negatively affected, and a further 5.4% stated that they had been affected for the better by the pandemic. Accounting for this influence means the results of the present study can be compared more effectively with past and future studies.

4.3. Conclusion

This study aimed to examine relationships between carer burden and depression and anxiety in older kinship carers, whilst exploring how self-compassion, dispositional mindfulness and mastery influenced these relationships. This study showed that carer burden is significantly positively correlated with both anxiety and depression. Through the use of conditional process analysis,

dispositional mindfulness and mastery were found to mediate the relationship between carer burden and depression. In the relationship between carer burden and anxiety, dispositional mindfulness was found to be a mediator, while self-compassion was found to moderate this relationship.

Kinship carers are often overlooked when it comes to policy, service provision and support. The findings of this study demonstrate that similar psychological factors may weaken the impact of stress as discovered in other caregiving populations. This provides a focus for intervention and highlights potential protective factors that can be harnessed to reduce the development of psychological distress in this population.

5. References

Age UK. (2022). *Poverty in later life*. Retrieved from https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/money-matters/poverty-in-later-life-briefing-january-2022-.pdf

Bazzano, A., Wolfe, C., Zylowska, L., Wang, S., Schuster, E., Barrett, C., & Lehrer, D. (2015). Mindfulness based stress reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: A community-based approach. *Journal of Child and Family Studies, 24*(2), 298-308. doi:10.1007/s10826-013-9836-9

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *The Gerontologist, 41*(5), 652-657. doi:10.1093/geront/41.5.652

Ben-Zur, H. (2002). Coping, affect and aging: The roles of mastery and self-esteem. *Personality and Individual Differences, 32*(2), 357-372. doi:10.1016/S0191-8869(01)00031-9

Bibou-Nakou, I., Dikaiou, M., & Bairactaris, C. (1997). Psychosocial dimensions of family burden among two groups of carers looking after psychiatric patients. *Social Psychiatry and Psychiatric Epidemiology, 32*(2), 104-108. doi:10.1007/BF00788928

Bowers, B. F., & Myers, B. J. (1999). Grandmothers providing care for grandchildren: Consequences of various levels of caregiving. *Family Relations*, 303-311. doi:10.2307/585641

Branger, C., O'Connell, M. E., & Morgan, D. G. (2016). Factor analysis of the 12-item Zarit Burden Interview in caregivers of persons diagnosed with dementia. *Journal of Applied Gerontology, 35*(5), 489-507. doi:10.1177/0733464813520222

Brown, K. W., & Ryan, R. M. (2003). The benefits of being present: mindfulness and its role in psychological well-being. *Journal of Personality and Social Psychology, 84*(4), 822. doi:10.1037/0022-3514.84.4.822

Cairney, J., & Krause, N. (2008). Negative life events and age-related decline in mastery: Are older adults more vulnerable to the control-eroding effect of stress? *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 63*(3), S162-S170. doi:10.1093/geronb/63.3.S162

Chan, E.-Y., Glass, G., Chua, K.-C., Ali, N., & Lim, W.-S. (2018). Relationship between mastery and caregiving competence in protecting against burden, anxiety and depression among caregivers of frail older adults. *The Journal of Nutrition, Health & Aging, 22*(10), 1238-1245. doi:10.1007/s12603-018-1098-1

Conway, P., Boeckel, J., Shuster, L., & Wages, J. (2010). Grandparent caregivers' use of resources and services, level of burden, and factors that mediate their relationships. *Journal of Intergenerational Relationships, 8*(2), 128-144. doi:10.1080/15350771003741931

del-Pino-Casado, R., Priego-Cubero, E., López-Martínez, C., & Orgeta, V. (2021). Subjective caregiver burden and anxiety in informal caregivers: A systematic review and meta-analysis. *PLOS One, 16*(3), e0247143. doi:10.1371/journal.pone.0247143

Dixon, H. C., & Overall, N. C. (2016). Dispositional mindfulness attenuates the link between daily stress and depressed mood. *Journal of Social and Clinical Psychology, 35*(3), 255-268. doi:10.1521/jscp.2016.35.3.255

Dunne, E. G., & Kettler, L. J. (2008). Grandparents raising grandchildren in Australia: Exploring psychological health and grandparents' experience of providing kinship care. *International Journal of Social Welfare, 17*(4), 333-345. doi:10.1111/j.1468-2397.2007.00529.x

Elmore, D. L. (2014). The impact of caregiving on physical and mental health: Implications for research, practice, education, and policy. In *The challenges of mental health caregiving* (pp. 15-31). Springer. doi:10.1007/978-1-4614-8791-3_2

Ewert, C., Vater, A., & Schröder-Abé, M. (2021). Self-compassion and coping: a meta-analysis. *Mindfulness, 12*(5), 1063-1077. doi:10.1007/s12671-020-01563-8

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*(2), 175-191. doi:10.3758/BF03193146

Fauth, E. B., Novak, J. R., & Levin, M. E. (2021). Outcomes from a pilot online Acceptance and Commitment Therapy program for dementia family caregivers. *Aging & Mental Health*, 1-10.

Field, A. (2013). *Discovering statistics using IBM SPSS statistics.* Sage. doi:10.1080/13607863.2021.1942432

Finlay-Jones, A. L. (2017). The relevance of self-compassion as an intervention target in mood and anxiety disorders: A narrative review based on an emotion regulation framework. *Clinical Psychologist, 21*(2), 90-103. doi:10.1111/cp.12131

Force, L. T., Botsford, A., Pisano, P. A., & Holbert, A. (2000). Grandparents raising children with and without a developmental disability: Preliminary comparisons. *Journal of Gerontological Social Work, 33*(4), 5-21. doi:10.1300/J083v33n04_02

Fritz, M. S., & MacKinnon, D. P. (2007). Required sample size to detect the mediated effect. *Psychological Science, 18*(3), 233-239. doi:10.1111/j.1467-9280.2007.01882.x

Garcia, A., O'Reilly, A., Matone, M., Kim, M., Long, J., & Rubin, D. M. (2015). The influence of caregiver depression on children in non-relative foster care versus kinship care placements. *Maternal and Child Health Journal, 19*(3), 459-467. doi:10.1007/s10995-014-1525-9

Geng, H.-m., Chuang, D.-m., Yang, F., Yang, Y., Liu, W.-m., Liu, L.-h., & Tian, H.-m. (2018). Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. *Medicine, 97*(39). doi:10.1097/MD.0000000000011863

Gilbert, P. (2005). *Compassion: Conceptualisations, research and use in psychotherapy*. Routledge.

Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in Psychiatric Treatment, 15*(3), 199-208. doi:10.1192/apt.bp.107.005264

Gloster, A. T., Rhoades, H. M., Novy, D., Klotsche, J., Senior, A., Kunik, M., . . . Stanley, M. A. (2008). Psychometric properties of the Depression Anxiety and Stress Scale-21 in older primary care patients. *Journal of Affective Disorders, 110*(3), 248-259. doi:10.1016/j.jad.2008.01.023

Gratão, A. C. M., Brigola, A. G., Ottaviani, A. C., Luchesi, B. M., Souza, É. N., Rossetti, E. S., . . . Pavarini, S. C. I. (2019). Brief version of Zarit Burden Interview (ZBI) for burden assessment in older caregivers. *Dementia & Neuropsychologia, 13*, 122-129. doi:10.1590/1980-57642018dn13-010015

Green, S. B. (1991). How many subjects does it take to do a regression analysis. *Multivariate Behavioral Research, 26*(3), 499-510. doi:10.1207/s15327906mbr2603_7

Hagell, P., Alvariza, A., Westergren, A., & Årestedt, K. (2017). Assessment of burden among family caregivers of people with Parkinson's disease using the Zarit Burden Interview. *Journal of Pain and Symptom Management, 53*(2), 272-278. doi:10.1016/j.jpainsymman.2016.09.007

Hair, J. F., Hult, G. T. M., Ringle, C. M., Sarstedt, M., Richter, N. F., & Hauff, S. (2017). *Partial Least Squares Structural Equation Modeling: An Application-Oriented Introduction*. Springer.

Harding, L., Murray, K., Shakespeare-Finch, J., & Frey, R. (2020). The wellbeing of foster and kin carers: A comparative study. *Children and Youth Services Review, 108*, 104566. doi:10.15358/9783800653614

Hayes, A. F. (2017). *Introduction to mediation, moderation, and conditional process analysis: A regression-based approach*. Guilford publications.

Hayes, S., Strosahl, K., & Wilson, K. (2012). Acceptance and Commitment Therapy: Second addition, the process and practice of mindful change. *Gulford*.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2009). *Acceptance and commitment therapy*. American Psychological Association.

Hayslip Jr, B., & Kaminski, P. L. (2005). Grandparents raising their grandchildren: A review of the literature and suggestions for practice. *The Gerontologist, 45*(2), 262-269. doi:10.1093/geront/45.2.262

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology, 44*(2), 227-239. doi:10.1348/014466505X29657

Hicks, A., Phillips, K., Siwik, C., Salmon, P., Litvan, I., Jablonski, M. E., . . . Sephton, S. E. (2019). The role of dispositional mindfulness in a stress-health pathway among Parkinson's disease patients and caregiving partners. *Quality of Life Research, 28*(10), 2705-2716. doi:10.1007/s11136-019-02217-6

Hsieh, C. C., Yu, C. J., Chen, H. J., Chen, Y. W., Chang, N. T., & Hsiao, F. H. (2019). Dispositional mindfulness, self-compassion, and compassion from others as moderators between stress and depression in caregivers of patients with lung cancer. *Psycho-Oncology, 28*(7), 1498-1505. doi:10.1002/pon.5106

Hughes, M., Brown, S. L., Campbell, S., Dandy, S., & Cherry, M. G. (2021). Self-compassion and anxiety and depression in chronic physical illness populations: A systematic review. *Mindfulness, 12*(7), 1597-1610. doi:10.1007/s12671-021-01602-y

Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: past, present, and future. *Clinical Psychology: Science and Practice, 10*(2), 144-156. doi:10.1093/clipsy.bpg016

Khalaila, R., & Cohen, M. (2016). Emotional suppression, caregiving burden, mastery, coping strategies and mental health in spousal caregivers. *Aging & Mental Health, 20*(9), 908-917. doi:10.1080/13607863.2015.1055551

Kinship. (2021). *Kinship Care: State of the Nation Survey 2021*. Retrieved from https://kinship.org.uk/kinship-annual-survey-2021/

Kiraly, M. (2015). *A review of kinship carer surveys: The "Cinderella" of the care system?* Retrieved from https://aifs.gov.au/cfca/sites/default/files/publication-documents/cfca-paper31.pdf
Koyama, A., Matsushita, M., Hashimoto, M., Fujise, N., Ishikawa, T., Tanaka, H., . . . Ikeda, M. (2017). Mental health among younger and older caregivers of dementia patients. *Psychogeriatrics, 17*(2), 108-114. doi:10.1111/psyg.12200
Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer.
Li, G., Yuan, H., & Zhang, W. (2016). The effects of mindfulness-based stress reduction for family caregivers: Systematic review. *Archives of Psychiatric Nursing, 30*(2), 292-299. doi:10.1016/j.apnu.2015.08.014
Little, R. J., & Rubin, D. B. (1989). The analysis of social science data with missing values. *Sociological Methods & Research, 18*(2-3), 292-326. doi:10.1177/0049124189018002004
Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy, 33*(3), 335-343. doi:10.1016/0005-7967(94)00075-U
Magnacca, C., Thomson, K., & Marcinkiewicz, A. (2021). Acceptance and commitment therapy for caregivers of children with neurodevelopmental disabilities: A systematic review. *Current Developmental Disorders Reports, 8*(2), 152-160. doi:10.1007/s40474-021-00228-y
Mathews, A. (1986). Cognitive processes in anxiety and depression: discussion paper. *Journal of the Royal Society of Medicine, 79*(3), 158-161. doi:10.1177/014107688607900309
Mausbach, B. T., Roepke, S. K., Chattillion, E. A., Harmell, A. L., Moore, R., Romero-Moreno, R., . . . Grant, I. (2012). Multiple mediators of the relations between caregiving stress and depressive symptoms. *Aging & Mental Health, 16*(1), 27-38. doi:10.1080/13607863.2011.615738
McAuliffe, L., Ong, B., & Kinsella, G. (2020). Mediators of burden and depression in dementia family caregivers: Kinship differences. *Dementia, 19*(7), 2234-2250. doi:10.1177/1471301218819345
Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity, 2*(3), 223-250. doi:10.1080/15298860309027
Neff, K. D., Hsieh, Y.-P., & Dejitterat, K. (2005). Self-compassion, achievement goals, and coping with academic failure. *Self and Identity, 4*(3), 263-287. doi:10.1080/13576500444000317
Office of National Statistics, O. (2021). *Overview of the UK population: January 2021*. Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2020basedinterim#changing-age-structure
Pagnini, F., Phillips, D., Bosma, C. M., Reece, A., & Langer, E. (2016). Mindfulness as a protective factor for the burden of caregivers of amyotrophic lateral sclerosis patients. *Journal of Clinical Psychology, 72*(1), 101-111. doi:10.1002/jclp.22235
Pasalich, D. S., Moretti, M. M., Hassall, A., & Curcio, A. (2021). Pilot randomized controlled trial of an attachment-and trauma-focused intervention for kinship caregivers. *Child Abuse & Neglect, 120*, 105178. doi:10.1016/j.chiabu.2021.105178
Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594. doi:10.1093/geront/30.5.583
Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, 19, 2-21. doi:10.2307/2136319
Pierce, M., Hope, H., Ford, T., Hatch, S., Hotopf, M., John, A., . . . McManus, S. (2020). Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. *The Lancet Psychiatry, 7*(10), 883-892. doi:10.1016/S2215-0366(20)30308-4
Raes, F., Pommier, E., Neff, K. D., & Van Gucht, D. (2011). Construction and factorial validation of a short form of the self-compassion scale. *Clinical Psychology & Psychotherapy, 18*(3), 250-255. doi:10.1002/cpp.702
Rock, S., Michelson, D., Thomson, S., & Day, C. (2015). Understanding foster placement instability for looked after children: A systematic review and narrative synthesis of quantitative and qualitative evidence. *British Journal of Social Work, 45*(1), 177-203. doi:10.1093/bjsw/bct084
Scottish Government. (2021). *Children's social work statistics:2019 to 2020*. Scotland: Scottish Government Retrieved from https://www.gov.scot/publications/childrens-social-work-statistics-2019-20/pages/3/
Selwyn, J., & Nandy, S. (2012). Sibling kinship carers in England: Evidence from the 2001 UK population census. *Children and Youth Services Review, 34*(1), 194-199. doi:10.1016/j.childyouth.2011.09.015
Sharda, E. A., Sutherby, C. G., Cavanaugh, D. L., Hughes, A. K., & Woodward, A. T. (2019). Parenting stress, well-being, and social support among kinship caregivers. *Children and Youth Services Review, 99*, 74-80. doi:10.1016/j.childyouth.2019.01.025

Sheridan, R., Martin-Kerry, J., Hudson, J., Parker, A., Bower, P., & Knapp, P. (2020). Why do patients take part in research? An overview of systematic reviews of psychosocial barriers and facilitators. *Trials, 21*(1), 1-18. doi:10.1186/s13063-020-4197-3

Springate, B. A., & Tremont, G. (2014). Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *The American Journal of Geriatric Psychiatry, 22*(3), 294-300. doi:10.1016/j.jagp.2012.09.006

Tagliabue, S., & Donato, S. (2015). Missing data in family research: Examining different levels of missingness. *TPM: Testing, Psychometrics, Methodology in Applied Psychology, 22*(2), 199-207. doi:10.4473/TPM22.2.3

Tomlinson, E. R., Yousaf, O., Vittersø, A. D., & Jones, L. (2018). Dispositional mindfulness and psychological health: a systematic review. *Mindfulness, 9*(1), 23-43. doi:10.1007/s12671-017-0762-6

Wellard, S., S. Meakings, E. Farmer, and J. Hunt. (2017). *Growing Up in Kinship Care: Experiences as Adolescents and Outcomes in Young Adulthood: Executive Summary*. Retrieved from https://research-information.bris.ac.uk/ws/portalfiles/portal/174570218/web100_Kinship_Care_7_.pdf

Wilson, A. C., Mackintosh, K., Power, K., & Chan, S. W. (2019). Effectiveness of self-compassion related therapies: a systematic review and meta-analysis. *Mindfulness, 10*(6), 979-995. doi:10.1007/s12671-018-1037-6

Winokur, M., Holtan, A., & Batchelder, K. E. (2014). Kinship care for the safety, Permanency, and Well-being of children removed from the home for maltreatment: a systematic review. *Campbell Systematic Reviews, 10*(1), 1-292. doi:10.4073/csr.2014.2

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist, 20*(6), 649-655. doi:10.1093/geront/20.6.649

Thesis Portfolio References

Age UK. (2022). *Poverty in later life*. Retrieved from https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/money-matters/poverty-in-later-life-briefing-january-2022-.pdf

Ahmadpanah, M., Akbari, T., Akhondi, A., Haghighi, M., Jahangard, L., Bahmani, D. S., . . . Brand, S. (2017). Detached mindfulness reduced both depression and anxiety in elderly women with major depressive disorders. *Psychiatry Research, 257*, 87-94. doi:10.1016/j.psychres.2017.07.030

Aldwin, C. M., Yancura, L., & Lee, H. (2021). Stress, coping, and aging. In *Handbook of the Psychology of Aging* (pp. 275-286). Elsevier.

Anderson, S. F., Kelley, K., & Maxwell, S. E. (2017). Sample-size planning for more accurate statistical power: A method adjusting sample effect sizes for publication bias and uncertainty. *Psychological Science, 28*(11), 1547-1562. doi:10.1177/0956797617723724

Andreas, S., Schulz, H., Volkert, J., Dehoust, M., Sehner, S., Suling, A., . . . Da Ronch, C. (2017). Prevalence of mental disorders in elderly people: the European MentDis_ICF65+ study. *The British Journal of Psychiatry, 210*(2), 125-131. doi:10.1192/bjp.bp.115.180463

Balsamo, M., Cataldi, F., Carlucci, L., & Fairfield, B. (2018). Assessment of anxiety in older adults: a review of self-report measures. *Clinical Interventions in Aging, 13*, 573. doi:10.2147/CIA.S114100

Bazzano, A., Wolfe, C., Zylowska, L., Wang, S., Schuster, E., Barrett, C., & Lehrer, D. (2015). Mindfulness based stress reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: A community-based approach. *Journal of Child and Family Studies, 24*(2), 298-308. doi:10.1007/s10826-013-9836-9

Beaunoyer, E., Landreville, P., & Carmichael, P.-H. (2019). Older adults' knowledge of anxiety disorders. *The Journals of Gerontology: Series B, 74*(5), 806-814. doi:10.1093/geronb/gbx128

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *The Gerontologist, 41*(5), 652-657. doi:10.1093/geront/41.5.652

Ben-Zur, H. (2002). Coping, affect and aging: The roles of mastery and self-esteem. *Personality and Individual Differences, 32*(2), 357-372. doi:10.1016/S0191-8869(01)00031-9

Bibou-Nakou, I., Dikaiou, M., & Bairactaris, C. (1997). Psychosocial dimensions of family burden among two groups of carers looking after psychiatric patients. *Social Psychiatry and Psychiatric Epidemiology, 32*(2), 104-108. doi:10.1007/BF00788928

Boone, M. S., Mundy, B., Morrissey Stahl, K., & Genrich, B. E. (2015). Acceptance and commitment therapy, functional contextualism, and clinical social work. *Journal of Human Behavior in the Social Environment, 25*(6), 643-656. doi:10.1080/10911359.2015.1011255

Bowers, B. F., & Myers, B. J. (1999). Grandmothers providing care for grandchildren: Consequences of various levels of caregiving. *Family Relations*, 303-311. doi:10.2307/585641

Branger, C., O'Connell, M. E., & Morgan, D. G. (2016). Factor analysis of the 12-item Zarit Burden Interview in caregivers of persons diagnosed with dementia. *Journal of Applied Gerontology, 35*(5), 489-507. doi:10.1177/0733464813520222

Brown, K. W., & Ryan, R. M. (2003). The benefits of being present: mindfulness and its role in psychological well-being. *Journal of Personality and Social Psychology, 84*(4), 822. doi:10.1037/0022-3514.84.4.822

Bryant, C., Jackson, H., & Ames, D. (2008). The prevalence of anxiety in older adults: methodological issues and a review of the literature. *Journal of Affective Disorders, 109*(3), 233-250. doi:10.1016/j.jad.2007.11.008

Burlingame, G. M., Fuhriman, A., & Johnson, J. E. (2001). Cohesion in group psychotherapy. *Psychotherapy: Theory, Research, Practice, Training, 38*(4), 373. doi:10.1037/0033-3204.38.4.373

Cairney, J., & Krause, N. (2008). Negative life events and age-related decline in mastery: Are older adults more vulnerable to the control-eroding effect of stress? *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 63*(3), S162-S170. doi:10.1093/geronb/63.3.S162

Chan, E.-Y., Glass, G., Chua, K.-C., Ali, N., & Lim, W.-S. (2018). Relationship between mastery and caregiving competence in protecting against burden, anxiety and depression among caregivers of frail older adults. *The Journal of Nutrition, Health & Aging, 22*(10), 1238-1245. doi:10.1007/s12603-018-1098-1

Chiesa, A., & Malinowski, P. (2011). Mindfulness-based approaches: Are they all the same? *Journal of Clinical Psychology, 67*(4), 404-424. doi:10.1002/jclp.20776

Conway, P., Boeckel, J., Shuster, L., & Wages, J. (2010). Grandparent caregivers' use of resources and services, level of burden, and factors that mediate their relationships. *Journal of Intergenerational Relationships, 8*(2), 128-144. doi:10.1080/15350771003741931
Corbett, C., Egan, J., & Pilch, M. (2019). A randomised comparison of two stress control programmes: progressive muscle relaxation versus mindfulness body scan. *Mental Health & Prevention, 15*, 200163. doi:10.1016/j.mph.2019.200163
Coupland, C., Dhiman, P., Morriss, R., Arthur, A., Barton, G., & Hippisley-Cox, J. (2011). Antidepressant use and risk of adverse outcomes in older people: population based cohort study. *British Medical Journal, 343*, 4551. doi:10.1136/bmj.d4551
Davison, T. E., Eppingstall, B., Runci, S., & O'Connor, D. W. (2017). A pilot trial of acceptance and commitment therapy for symptoms of depression and anxiety in older adults residing in long-term care facilities. *Aging & Mental Health, 21*(7), 766-773. doi:10.1080/13607863.2016.1156051
del-Pino-Casado, R., Priego-Cubero, E., López-Martínez, C., & Orgeta, V. (2021). Subjective caregiver burden and anxiety in informal caregivers: A systematic review and meta-analysis. *PLOS One, 16*(3), e0247143. doi:10.1371/journal.pone.0247143
Dixon, H. C., & Overall, N. C. (2016). Dispositional mindfulness attenuates the link between daily stress and depressed mood. *Journal of Social and Clinical Psychology, 35*(3), 255-268. doi:10.1521/jscp.2016.35.3.255
Dunne, E. G., & Kettler, L. J. (2008). Grandparents raising grandchildren in Australia: Exploring psychological health and grandparents' experience of providing kinship care. *International Journal of Social Welfare, 17*(4), 333-345. doi:10.1111/j.1468-2397.2007.00529.x
Elmore, D. L. (2014). The impact of caregiving on physical and mental health: Implications for research, practice, education, and policy. In *The challenges of mental health caregiving* (pp. 15-31). Springer. doi:10.1007/978-1-4614-8791-3_2
Ewert, C., Vater, A., & Schröder-Abé, M. (2021). Self-compassion and coping: a meta-analysis. *Mindfulness, 12*(5), 1063-1077. doi:10.1007/s12671-020-01563-8
Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*(2), 175-191. doi:10.3758/BF03193146
Fauth, E. B., Novak, J. R., & Levin, M. E. (2021). Outcomes from a pilot online Acceptance and Commitment Therapy program for dementia family caregivers. *Aging & Mental Health*, 1-10.
Feigenbaum, J. (2007). Dialectical behaviour therapy: An increasing evidence base. *Journal of Mental Health, 16*(1), 51-68. doi:10.1080/09638230601182094
Field, A. (2013). *Discovering statistics using IBM SPSS statistics.* Sage. doi:10.1080/13607863.2021.1942432
Finlay-Jones, A. L. (2017). The relevance of self-compassion as an intervention target in mood and anxiety disorders: A narrative review based on an emotion regulation framework. *Clinical Psychologist, 21*(2), 90-103. doi:10.1111/cp.12131
Forbes, M., Crome, E., Sunderland, M., & Wuthrich, V. (2017). Perceived needs for mental health care and barriers to treatment across age groups. *Aging & mental health, 21*(10), 1072-1078. doi:10.1080/13607863.2016.1193121
Force, L. T., Botsford, A., Pisano, P. A., & Holbert, A. (2000). Grandparents raising children with and without a developmental disability: Preliminary comparisons. *Journal of Gerontological Social Work, 33*(4), 5-21. doi:10.1300/J083v33n04_02
Francis, G. (2012). Publication bias and the failure of replication in experimental psychology. *Psychonomic Bulletin & Review, 19*(6), 975-991. doi:10.3758/s13423-012-0322-y
Franco, C., Amutio, A., Mañas, I., Gázquez, J. J., & del Carmen Pérez-Fuentes, M. (2017). Reducing anxiety, geriatric depression and worry in a sample of older adults through a mindfulness training program.*Terapia Psicológica, 35*(1), 71-79. doi:10.4067/S0718-48082017000100007
Fritz, M. S., & MacKinnon, D. P. (2007). Required sample size to detect the mediated effect. *Psychological Science, 18*(3), 233-239. doi:10.1111/j.1467-9280.2007.01882.x
Gaglio, B., Phillips, S. M., Heurtin-Roberts, S., Sanchez, M. A., & Glasgow, R. E. (2014). How pragmatic is it? Lessons learned using PRECIS and RE-AIM for determining pragmatic characteristics of research. *Implementation Science, 9*(1), 1-11. doi:10.1186/s13012-014-0096-x
Garcia, A., O'Reilly, A., Matone, M., Kim, M., Long, J., & Rubin, D. M. (2015). The influence of caregiver depression on children in non-relative foster care versus kinship care placements. *Maternal and Child Health Journal, 19*(3), 459-467. doi:10.1007/s10995-014-1525-9

Geiger, P. J., Boggero, I. A., Brake, C. A., Caldera, C. A., Combs, H. L., Peters, J. R., & Baer, R. A. (2016). Mindfulness-based interventions for older adults: A review of the effects on physical and emotional well-being. *Mindfulness, 7*(2), 296-307. doi:10.1007/s12671-015-0444-1

Geng, H.-m., Chuang, D.-m., Yang, F., Yang, Y., Liu, W.-m., Liu, L.-h., & Tian, H.-m. (2018). Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. *Medicine, 97*(39). doi:10.1097/MD.0000000000011863

Gilbert, P. (2005). *Compassion: Conceptualisations, research and use in psychotherapy.* Routledge.

Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in Psychiatric Treatment, 15*(3), 199-208. doi:10.1192/apt.bp.107.005264

Glasgow, R. E., Harden, S. M., Gaglio, B., Rabin, B., Smith, M. L., Porter, G. C., . . . Estabrooks, P. A. (2019). RE-AIM planning and evaluation framework: adapting to new science and practice with a 20-year review. *Frontiers in Public Health, 7*, 64. doi:10.3389/fpubh.2019.00064

Glasgow, R. E., Vogt, T. M., & Boles, S. M. (1999). Evaluating the public health impact of health promotion interventions: the RE-AIM framework. *American Journal of Public Health, 89*(9), 1322-1327. doi:10.2105/AJPH.89.9.1322

Gloster, A. T., Rhoades, H. M., Novy, D., Klotsche, J., Senior, A., Kunik, M., . . . Stanley, M. A. (2008). Psychometric properties of the Depression Anxiety and Stress Scale-21 in older primary care patients. *Journal of Affective Disorders, 110*(3), 248-259. doi:10.1016/j.jad.2008.01.023

Goldberg, S. B., Tucker, R. P., Greene, P. A., Davidson, R. J., Wampold, B. E., Kearney, D. J., & Simpson, T. L. (2018). Mindfulness-based interventions for psychiatric disorders: A systematic review and meta-analysis. *Clinical Psychology Review, 59*, 52-60. doi:10.1016/j.cpr.2017.10.011

Gonçalves, D. C., & Byrne, G. J. (2012). Interventions for generalized anxiety disorder in older adults: systematic review and meta-analysis. *Journal of Anxiety Disorders, 26*(1), 1-11. doi:10.1016/j.janxdis.2011.08.010

Gratão, A. C. M., Brigola, A. G., Ottaviani, A. C., Luchesi, B. M., Souza, É. N., Rossetti, E. S., . . . Pavarini, S. C. I. (2019). Brief version of Zarit Burden Interview (ZBI) for burden assessment in older caregivers. *Dementia & Neuropsychologia, 13*, 122-129. doi:10.1590/1980-57642018dn13-010015

Green, S. B. (1991). How many subjects does it take to do a regression analysis. *Multivariate Behavioral Research, 26*(3), 499-510. doi:10.1207/s15327906mbr2603_7

Grossman, P., Niemann, L., Schmidt, S., & Walach, H. (2004). Mindfulness-based stress reduction and health benefits: A meta-analysis. *Journal of Psychosomatic Research, 57*(1), 35-43. doi:10.1016/S0022-3999(03)00573-7

Hagell, P., Alvariza, A., Westergren, A., & Årestedt, K. (2017). Assessment of burden among family caregivers of people with Parkinson's disease using the Zarit Burden Interview. *Journal of Pain and Symptom Management, 53*(2), 272-278. doi:10.1016/j.jpainsymman.2016.09.007

Hair, J. F., Hult, G. T. M., Ringle, C. M., Sarstedt, M., Richter, N. F., & Hauff, S. (2017). *Partial Least Squares Structural Equation Modeling: An Application-Oriented Introduction*. Springer.

Harding, L., Murray, K., Shakespeare-Finch, J., & Frey, R. (2020). The wellbeing of foster and kin carers: A comparative study. *Children and Youth Services Review, 108*, 104566. doi:10.15358/9783800653614

Hayes, A. F. (2017). *Introduction to mediation, moderation, and conditional process analysis: A regression-based approach*. Guilford publications.

Hayes, S., Strosahl, K., & Wilson, K. (2012). Acceptance and Commitment Therapy: Second addition, the process and practice of mindful change. *Gulford*.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2009). *Acceptance and commitment therapy*. American Psychological Association.

Hayslip Jr, B., & Kaminski, P. L. (2005). Grandparents raising their grandchildren: A review of the literature and suggestions for practice. *The Gerontologist, 45*(2), 262-269. doi:10.1093/geront/45.2.262

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology, 44*(2), 227-239. doi:10.1348/014466505X29657

Hicks, A., Phillips, K., Siwik, C., Salmon, P., Litvan, I., Jablonski, M. E., . . . Sephton, S. E. (2019). The role of dispositional mindfulness in a stress-health pathway among Parkinson's disease patients and caregiving partners. *Quality of Life Research, 28*(10), 2705-2716. doi:10.1007/s11136-019-02217-6

Howard, G. S. (1980). Response-shift bias: A problem in evaluating interventions with pre/post self-reports. *Evaluation Review, 4*(1), 93-106. doi:10.1177/0193841X8000400105

Hsieh, C. C., Yu, C. J., Chen, H. J., Chen, Y. W., Chang, N. T., & Hsiao, F. H. (2019). Dispositional mindfulness, self-compassion, and compassion from others as moderators between stress and depression in caregivers of patients with lung cancer. *Psycho-Oncology, 28*(7), 1498-1505. doi:10.1002/pon.5106

Hughes, M., Brown, S. L., Campbell, S., Dandy, S., & Cherry, M. G. (2021). Self-compassion and anxiety and depression in chronic physical illness populations: A systematic review. *Mindfulness, 12*(7), 1597-1610. doi:10.1007/s12671-021-01602-y

Joanna Briggs Institute (Producer). (2017). Checklists for systematic review and research synthesis.

Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: past, present, and future. *Clinical Psychology: Science and Practice*, 10, 144-156. doi:10.1093/clipsy.bpg016

Kabat-Zinn, J., & Hanh, T. N. (2009). *Full catastrophe living: Using the wisdom of your body and mind to face stress, pain, and illness*. Delta.

Khalaila, R., & Cohen, M. (2016). Emotional suppression, caregiving burden, mastery, coping strategies and mental health in spousal caregivers. *Aging & Mental Health, 20*(9), 908-917. doi:10.1080/13607863.2015.1055551

Khoury, B., Sharma, M., Rush, S. E., & Fournier, C. (2015). Mindfulness-based stress reduction for healthy individuals: A meta-analysis. *Journal of Psychosomatic Research, 78*(6), 519-528. doi:10.1016/j.jpsychores.2015.03.009

Kinship. (2021). *Kinship Care: State of the Nation Survey 2021*. Retrieved from https://kinship.org.uk/kinship-annual-survey-2021/

Kiraly, M. (2015). *A review of kinship carer surveys: The "Cinderella" of the care system?* Retrieved from https://aifs.gov.au/cfca/sites/default/files/publication-documents/cfca-paper31.pdf

Kogan, J. N., Edelstein, B. A., & McKee, D. R. (2000). Assessment of anxiety in older adults: current status. *Journal of Anxiety Disorders, 14*(2), 109-132. doi:10.1016/S0887-6185(99)00044-4

Koyama, A., Matsushita, M., Hashimoto, M., Fujise, N., Ishikawa, T., Tanaka, H., . . . Ikeda, M. (2017). Mental health among younger and older caregivers of dementia patients. *Psychogeriatrics, 17*(2), 108-114. doi:10.1111/psyg.12200

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

Levy, M. (2018). *An Examination of a Mindfulness-Based Intervention for Older Adults* [Doctoral thesis, Nova Southeastern University]. ProQuest Dissertations and Theses Global. Retrieved from: https://www.proquest.com/pqdtglobal/docview/2116163736/A99648A72BCF4684PQ/1?accountid=10673

Li, S. Y. H., & Bressington, D. (2019). The effects of mindfulness-based stress reduction on depression, anxiety, and stress in older adults: A systematic review and meta-analysis. *International Journal of Mental Health Nursing, 28*(3), 635-656. doi:10.1111/inm.12568

Linehan, M. M. (2015). *DBT® Skills Training: manuale*. Cortina.

Little, R. J., & Rubin, D. B. (1989). The analysis of social science data with missing values. *Sociological Methods & Research, 18*(2-3), 292-326. doi:10.1177/0049124189018002004

Llewellyn-Bennett, R., Bowman, L., & Bulbulia, R. (2016). Post-trial follow-up methodology in large randomized controlled trials: a systematic review protocol. *Systematic Reviews, 5*(1), 1-7. doi:10.1186/s13643-016-0393-3

Lomas, T., Medina, J. C., Ivtzan, I., Rupprecht, S., & Eiroa-Orosa, F. J. (2019). Mindfulness-based interventions in the workplace: An inclusive systematic review and meta-analysis of their impact upon wellbeing. *The Journal of Positive Psychology, 14*(5), 625-640. doi:10.1080/17439760.2018.1519588

Longmore, R. J., & Worrell, M. (2007). Do we need to challenge thoughts in cognitive behavior therapy? *Clinical Psychology Review, 27*(2), 173-187. doi:10.1016/j.cpr.2006.08.001

Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy, 33*(3), 335-343. doi:10.1016/0005-7967(94)00075-U

Magnacca, C., Thomson, K., & Marcinkiewicz, A. (2021). Acceptance and commitment therapy for caregivers of children with neurodevelopmental disabilities: A systematic review. *Current Developmental Disorders Reports, 8*(2), 152-160. doi:10.1007/s40474-021-00228-y

Maltais, M., Bouchard, G., & Saint-Aubin, J. (2019). Mechanisms of mindfulness: The mediating roles of adaptive and maladaptive cognitive factors. *Current Psychology, 38*(3), 846-854. doi:10.1007/s12144-017-9665-x

Mathews, A. (1986). Cognitive processes in anxiety and depression: discussion paper. *Journal of the Royal Society of Medicine, 79*(3), 158-161. doi:10.1177/014107688607900309

Mausbach, B. T., Roepke, S. K., Chattillion, E. A., Harmell, A. L., Moore, R., Romero-Moreno, R., . . . Grant, I. (2012). Multiple mediators of the relations between caregiving stress and depressive symptoms. *Aging & Mental Health, 16*(1), 27-38. doi:10.1080/13607863.2011.615738

McAuliffe, L., Ong, B., & Kinsella, G. (2020). Mediators of burden and depression in dementia family caregivers: Kinship differences. *Dementia, 19*(7), 2234-2250. doi:10.1177/1471301218819345

Moghadam, K. K., Baharvandi, B., & Rashidi, H. H. (2020). The Effectiveness of compassion-focused therapy on ambiguity tolerance and death anxiety in the elderly. *Aging, 6*(1), 13-26. Retrieved from: https://jap.razi.ac.ir/mobile/article_1446_7f774fde0f3013c195d5f094bbb34968.pdf

Moss, A. S., Reibel, D. K., Greeson, J. M., Thapar, A., Bubb, R., Salmon, J., & Newberg, A. B. (2015). An adapted mindfulness-based stress reduction program for elders in a continuing care retirement community: Quantitative and qualitative results from a pilot randomized controlled trial. *Journal of Applied Gerontology, 34*(4), 518-538. doi:10.1177/0733464814559411

National Institute for Health and Care Excellence [NICE]. (2011). *Generalised anxiety disorder and panic disorder in adults: management*. Retrieved from https://www.nice.org.uk/guidance/cg113/chapter/Key-priorities-for-implementation

Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity, 2*(3), 223-250. doi:10.1080/15298860309027

Neff, K. D., Hsieh, Y.-P., & Dejitterat, K. (2005). Self-compassion, achievement goals, and coping with academic failure. *Self and Identity, 4*(3), 263-287. doi:10.1080/13576500444000317

Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., . . . Mulrow, C.D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *British Medical Journal, 372*(71). doi:10.1136/bmj.n71

Pagnini, F., Phillips, D., Bosma, C. M., Reece, A., & Langer, E. (2016). Mindfulness as a protective factor for the burden of caregivers of amyotrophic lateral sclerosis patients. *Journal of Clinical Psychology, 72*(1), 101-111. doi:10.1002/jclp.22235

Pasalich, D. S., Moretti, M. M., Hassall, A., & Curcio, A. (2021). Pilot randomized controlled trial of an attachment-and trauma-focused intervention for kinship caregivers. *Child Abuse & Neglect, 120*, 105178. doi:10.1016/j.chiabu.2021.105178

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594. doi:10.1093/geront/30.5.583

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, 19, 2-21. doi:10.2307/2136319

Pierce, M., Hope, H., Ford, T., Hatch, S., Hotopf, M., John, A., . . . McManus, S. (2020). Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. *The Lancet Psychiatry, 7*(10), 883-892. doi:10.1016/S2215-0366(20)30308-4

Pierson, M. M., Roche, A. I., & Denburg, N. L. (2019). Mindfulness, experiential avoidance, and affective experience in older adults. *Journal of Contextual Behavioral Science, 14*, 32-36. doi:10.1016/j.jcbs.2019.08.007

Raes, F., Pommier, E., Neff, K. D., & Van Gucht, D. (2011). Construction and factorial validation of a short form of the self-compassion scale. *Clinical Psychology & Psychotherapy, 18*(3), 250-255. doi:10.1002/cpp.702

Rapport, F., Clay-Williams, R., Churruca, K., Shih, P., Hogden, A., & Braithwaite, J. (2018). The struggle of translating science into action: foundational concepts of implementation science. *Journal of Evaluation in Clinical Practice, 24*(1), 117-126. doi:10.1111/jep.12741

Reangsing, C., Rittiwong, T., & Schneider, J. K. (2021). Effects of mindfulness meditation interventions on depression in older adults: A meta-analysis. *Aging & Mental Health, 25*(7), 1181-1190. doi:10.1080/13607863.2020.1793901

Rock, S., Michelson, D., Thomson, S., & Day, C. (2015). Understanding foster placement instability for looked after children: A systematic review and narrative synthesis of quantitative and qualitative evidence. *British Journal of Social Work, 45*(1), 177-203. doi:10.1093/bjsw/bct084

Russell, L., Ugalde, A., Milne, D., Austin, D., & Livingston, P. M. (2018). Digital characteristics and dissemination indicators to optimize delivery of internet-supported mindfulness-based interventions for people with a chronic condition: systematic review. *JMIR Mental Health, 5*(3), e9645. doi:10.2196/mental.9645

Scottish Government. (2021). *Children's social work statistics:2019 to 2020*. Scotland: Scottish Government Retrieved from https://www.gov.scot/publications/childrens-social-work-statistics-2019-20/pages/3/

Segal, Z. V., & Walsh, K. M. (2016). Mindfulness based cognitive therapy for residual depressive symptoms and relapse prophylaxis. *Current Opinion in Psychiatry, 29*(1), 7. doi:10.1097/YCO.0000000000000216

Segal, Z. V., Williams, M., & Teasdale, J. (2018). *Mindfulness-based cognitive therapy for depression*. Guilford Publications.

Selwyn, J., & Nandy, S. (2012). Sibling kinship carers in England: Evidence from the 2001 UK population census. *Children and Youth Services Review, 34*(1), 194-199. doi:10.1016/j.childyouth.2011.09.015

Sharda, E. A., Sutherby, C. G., Cavanaugh, D. L., Hughes, A. K., & Woodward, A. T. (2019). Parenting stress, well-being, and social support among kinship caregivers. *Children and Youth Services Review, 99*, 74-80. doi:10.1016/j.childyouth.2019.01.025

Sheridan, R., Martin-Kerry, J., Hudson, J., Parker, A., Bower, P., & Knapp, P. (2020). Why do patients take part in research? An overview of systematic reviews of psychosocial barriers and facilitators. *Trials, 21*(1), 1-18. doi:10.1186/s13063-020-4197-3

Smart, C. M., & Segalowitz, S. J. (2017). Respond, don't react: The influence of mindfulness training on performance monitoring in older adults. *Cognitive, Affective, & Behavioral Neuroscience, 17*(6), 1151-1163. doi:10.3758/s13415-017-0539-3

Song, C., Zhang, Y., & Wu, Z. (2021). Effect of mindfulness-based stress reduction therapy on psychological status and sleep quality of elderly patients with gastroesophageal reflux disease during COVID-19 pandemic. *World Chinese Journal of Digestology*, 48-52. doi:10.11569/wcjd.v29.i1.48

Springate, B. A., & Tremont, G. (2014). Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *The American Journal of Geriatric Psychiatry, 22*(3), 294-300. doi:10.1016/j.jagp.2012.09.006

Steptoe, A., Deaton, A., & Stone, A. A. (2015). Subjective wellbeing, health, and ageing. *The Lancet, 385*(9968), 640-648. doi:10.1016/S0140-6736(13)61489-0

Tagliabue, S., & Donato, S. (2015). Missing data in family research: Examining different levels of missingness. *TPM: Testing, Psychometrics, Methodology in Applied Psychology, 22*(2), 199-207. doi:10.4473/TPM22.2.3

Thilakan, P. (2020). Effectiveness of TIPER (Tailor Made Interventional Package to Enhance Relaxation) on Stress, Depression and Anxiety among Elders-A Pilot Study. *International Journal of Health Sciences and Research, 8*(3), 186-192. Retrieved from: https://d1wqtxts1xzle7.cloudfront.net/64027854/

Thomas, R., Chur-Hansen, A., & Turner, M. (2020). A systematic review of studies on the use of Mindfulness-Based Cognitive Therapy for the treatment of anxiety and depression in older people. *Mindfulness, 11*(7), 1599-1609. doi:10.1007/s12671-020-01336-3

Tkatch, R., Bazarko, D., Musich, S., Wu, L., MacLeod, S., Keown, K., . . . Wicker, E. (2017). A pilot online mindfulness intervention to decrease caregiver burden and improve psychological well-being. *Journal of Evidence-based Complementary & Alternative Medicine, 22*(4), 736-743. doi:10.1177/2156587217737204

Tomlinson, E. R., Yousaf, O., Vittersø, A. D., & Jones, L. (2018). Dispositional mindfulness and psychological health: a systematic review. *Mindfulness, 9*(1), 23-43. doi:10.1007/s12671-017-0762-6

Vela, R. H. (2004). *The effects of relaxation and meditation on assisted living residents, their neighbors, and the overall quality of life of the residential facility* [Doctoral thesis, The University of Kansas]. ProQuest Dissertations and Theses Global. Retrieved from: https://www.proquest.com/pqdtglobal/docview/305171564/465D85ED40454449PQ/1?accountid=10673

Wang, G., Albayrak, A., & van der Cammen, T. J. (2019). A systematic review of non-pharmacological interventions for BPSD in nursing home residents with dementia: from a perspective of ergonomics. *International Psychogeriatrics, 31*(8), 1137-1149. doi:10.1017/S1041610218001679

Wellard, S., S. Meakings, E. Farmer, and J. Hunt. (2017). *Growing Up in Kinship Care: Experiences as Adolescents and Outcomes in Young Adulthood: Executive Summary*. Retrieved from https://research-information.bris.ac.uk/ws/portalfiles/portal/174570218/web100_Kinship_Care_7_.pdf

Wilson, A. C., Mackintosh, K., Power, K., & Chan, S. W. (2019). Effectiveness of self-compassion related therapies: a systematic review and meta-analysis. *Mindfulness, 10*(6), 979-995. doi:10.1007/s12671-018-1037-6

Winokur, M., Holtan, A., & Batchelder, K. E. (2014). Kinship care for the safety, Permanency, and Well-being of children removed from the home for maltreatment: a systematic review. *Campbell Systematic Reviews, 10*(1), 1-292. doi:10.4073/csr.2014.2

Wong, S. Y. S., Zhang, D., Sit, R. W. S., Yip, B. H. K., Chung, R. Y.-n., Wong, C. K. M., . . . Mercer, S. W. (2020). Impact of COVID-19 on loneliness, mental health, and health service utilisation: a prospective cohort study of older adults with multimorbidity in primary care. *British Journal of General Practice, 70*(700), e817-e824. doi:10.3399/bjgp20X713021

World Health Organisation. (2021a). *Aging and Health: October 2021*. Retrieved from https://www.who.int/news-room/fact-sheets/detail/ageing-and-health

World Health Organisation. (2021b). *Comprehensive Mental Health Action Plan 2013-2030*. Retrieved from https://www.who.int/publications/i/item/9789240031029

Wuthrich, V. M., Johnco, C. J., & Wetherell, J. L. (2015). Differences in anxiety and depression symptoms: comparison between older and younger clinical samples. *International Psychogeriatrics, 27*(9), 1523-1532. doi:10.1017/S1041610215000526

Wuthrich, V. M., Meuldijk, D., Jagiello, T., Robles, A. G., Jones, M. P., & Cuijpers, P. (2021). Efficacy and effectiveness of psychological interventions on co-occurring mood and anxiety disorders in older adults: A systematic review and meta-analysis. *International Journal of Geriatric Psychiatry, 36*(6), 858-872. doi:10.1002/gps.5486

Xu, S., Zhang, H., & Wang, J. (2020). Caregiver burden and depression among Chinese family caregivers: the role of self-compassion. *Mindfulness, 11*(7), 1647-1654. doi:10.1007/s12671-020-01378-7

Yang, Y. (2007). Is old age depressing? Growth trajectories and cohort variations in late-life depression. *Journal of Health and Social Behavior, 48*(1), 16-32. doi:10.1177/002214650704800102

Yates, B. T. (2020). Research on improving outcomes and reducing costs of psychological interventions: Toward delivering the best to the most for the least. *Annual Review of Clinical Psychology, 16*, 125-150. doi:10.1146/annurev-clinpsy-071519-110415

Young, L. A., & Baime, M. J. (2010). Mindfulness-based stress reduction: Effect on emotional distress in older adults. *Complementary Health Practice Review, 15*(2), 59-64. doi:10.1177/1533210110387687

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist, 20*(6), 649-655. doi:10.1093/geront/20.6.649

Zhang, J.-x., Liu, X.-h., Xie, X.-h., Zhao, D., Shan, M.-s., Zhang, X.-l., . . . Cui, H. (2015). Mindfulness-based stress reduction for chronic insomnia in adults older than 75 years: a randomized, controlled, single-blind clinical trial. *Explore, 11*(3), 180-185. doi:10.1016/j.explore.2015.02.005

Zollars, I., Poirier, T. I., & Pailden, J. (2019). Effects of mindfulness meditation on mindfulness, mental well-being, and perceived stress. *Currents in Pharmacy Teaching and Learning, 11*(10), 1022-1028. doi:10.1016/j.cptl.2019.06.005

Appendices

Appendix A: Submission Guidelines for the Journal of Behaviour Research and Therapy

DESCRIPTION .

The major focus of Behaviour Research and Therapy is an experimental psychopathology approach to understanding emotional and behavioral disorders and their prevention and treatment, using cognitive, behavioral, and psychophysiological (including neural) methods and models. This includes laboratory-based experimental studies with healthy, at risk and subclinical individuals that inform clinical application as well as studies with clinically severe samples. The following types of submissions are encouraged: theoretical reviews of mechanisms that contribute to psychopathology and that offer new treatment targets; tests of novel, mechanistically focused psychological interventions, especially ones that include theory-driven or experimentally-derived predictors, moderators and mediators; and innovations in dissemination and implementation of evidence-based practices into clinical practice in psychology and associated fields, especially those that target underlying mechanisms or focus on novel approaches to treatment delivery. In addition to traditional psychological disorders, the scope of the journal includes behavioural medicine (e.g., chronic pain). The journal will not consider manuscripts dealing primarily with measurement, psychometric analyses, and personality assessment. The Editor and Associate Editors will make an initial determination of whether or not submissions fall within the scope of the journal and/or are of sufficient merit and importance to warrant full review.

AUDIENCE .

For clinical psychologists, psychiatrists, psychotherapists, psychoanalysts, social workers, counsellors, medical psychologists, and other mental health workers.

IMPACT FACTOR .

2020: 4.473 © Clarivate Analytics Journal Citation Reports 2021

AUTHOR GUIDELINES

Preparation

While full-length articles have no explicit limits in terms of numbers of words, tables/figures, and references, an article's length must be justified by its empirical strength and the significance of its contribution to the literature

Article structure

Subdivision - unnumbered sections

Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when cross-referencing text: refer to the subsection by heading as opposed to simply 'the text'.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Essential title page information

• ***Title*.** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

• ***Author names and affiliations***. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. You can add your name between parentheses in your own script behind the English transliteration. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lowercase superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

• ***Corresponding author***. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. This responsibility includes answering any future queries about

Methodology and Materials. Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.

• **Present/permanent address.** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes

Abstract

A concise and factual abstract is required with a maximum length of 200 words. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, to be chosen from the APA list of index descriptors. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Tables Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

Reference style

Text: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Seventh Edition, ISBN 978-1-4338-3215-4, copies of which may be ordered online.

List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

Appendix B- Breakdown of Systematic Review Critical Appraisal of included studies

	Ahmadpanah et al. (2017)	Franco et al. (2017)	Levy & DeLucia (2018)	Moss et al. (2015)	Thilakan et al. (2020)	Smart & Segalowitz (2017)	Song et al. (2021)	Tkatch et al. (2017)	Vela (2006)	Young & Baime (2010)	Zhang et al. (2015)
RANDOMISED CONTROL TRIALS											
1. Was true randomization used for assignment of participants to treatment groups?	Y	Y		Y	Y	Y	Y				Y
2. Was allocation to treatment groups concealed?	U	U		U	U	Y	U				U
3. Were treatment groups similar at the baseline?	Y	Y		Y	U	Y	Y				Y
4. Were participants blind to treatment assignment?	N/A	N/A		N/A	N/A	N/A	N/A				N/A
5. Were those delivering treatment blind to treatment assignment?	N/A	N/A		N/A	N/A	N/A	N/A				N/A
6. Were outcomes assessors blind to treatment assignment?	Y	N		Y	N	N	N				N
7. Were treatment groups treated identically other than the intervention of interest?	Y	Y		Y	U	N	Y				Y
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Y	Y		Y	Y	Y	Y				Y
9. Were participants analysed in the groups to which they were randomized?	Y	Y		Y	Y	Y	Y				Y
10. Were outcomes measured in the same way for treatment groups?	Y	Y		Y	Y	Y	Y				Y
11. Were outcomes measured in a reliable way?	Y	Y		Y	Y	Y	Y				Y
12. Was appropriate statistical analysis used?	Y	Y		Y	Y	Y	Y				Y
13. Was the trial design appropriate, and any deviations from the standard RCT	Y	Y		Y	Y	Y	Y				Y

design accounted for in the conduct and analysis of the trial?											
QUASI- EXPERIMENTAL STUDIES											
1. Is it clear in the study what is the 'cause' and what is the 'effect'?			Y					Y	Y	Y	
2. Were the participants included in any comparisons similar?			N					Y	Y	Y	
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?			Y					Y	Y	Y	
4. Was there a control group?			Y					N	Y	N	
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?			Y					Y	Y	N	
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?			Y					Y	Y	Y	
7. Were the outcomes of participants included in any comparisons measured in the same way?			Y					Y	Y	Y	
8. Were outcomes measured in a reliable way?			Y					Y	Y	Y	
9. Was appropriate statistical analysis used?			Y					Y	Y	Y	
PERCENTAGE CRITERIA MET	**91%**	**82%**	**89%**	**100%**	**64%**	**82%**	**82%**	**89%**	**100%**	**78%**	**82%**

Y= Yes, N= No, N/A= Not applicable

Appendix C- Systematic Review RE-AIM analysis of included studies

	Ahmadpanah et al. (2017)	Franco et al. (2017)	Levy & DeLucia (2018)	Moss et al. (2015)	Thilakan et al. (2020)	Smart & Segalowitz (2017)	Song et al. (2021)	Tkatch et al. (2017)	Vela (2006)	Young & Baime (2010)	Zhang et al. (2015)
REACH											
1. Method to identify target population	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Inclusion Criteria	Y	N	Y	Y	Y	Y	Y	Y	N	N	Y
3. Exclusion Criteria	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y
4. Participation Rate	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
5. Representativeness	N	N	N	N	N	N	N	N	N	N	N
EFFICACY											
6. Measures/ results for at least one follow-up	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
7. Intent-to-treat analysis	Y	Y	Y	Y	Y	N	Y	Y	Y	N/A	Y
8. Quality of life of potential negative outcomes	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
9. Percent attrition	Y	N	Y	Y	N	Y	N	Y	Y	N	Y
ADOPTION											
10. Description of intervention location	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
11. Description of staff who delivered intervention	Y	N	Y	Y	N	N	N	Y	Y	N	Y
12. Method to identify staff who delivered intervention (target delivery agent)	N	N	N	N	N	N	N	N	Y	N	N
13. Level of expertise of delivery agent	Y	N	Y	Y	N	N	N	Y	Y	N	Y
14. Inclusion/ exclusion of delivery agent	N	N	N	N	N	N	N	N	N	N	N
15. Adoption rate of delivery agent	N	N	N	N	N	N	N	N	N	N	N
IMPLEMENTATION											
16. Intervention duration and frequency	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
17. Extent protocol delivered as intended (%)	N	N	N	N	N	N	N	N	Y	N	N
18. Measures of cost of implementation	N	N	N	N	N	N	N	N	N	N	N
MAINTENANCE											
19. Assessed outcomes at 6 months or over post intervention	N	N	N	N	N	N	N	N	N	N	N
20. Indicators of program-level maintenance supporting text	N	N	N	N	N	N	N	N	N	N	N
21. Measures of cost maintenance	N	N	N	N	N	N	N	Y	N	N	N

Y= Yes, N= No, N/A= Not applicable

Appendix D: Submission guidelines for the Journal of Child & Family Social Work

AIMS AND SCOPE

Child & Family Social Work provides a forum where researchers, practitioners, policy-makers and managers in the field exchange knowledge, increase understanding and develop notions of good practice. In its promotion of research and practice, which is both disciplined and articulate, the Journal is dedicated to advancing the wellbeing and welfare of children and their families throughout the world.

Child & Family Social Work publishes original and distinguished contributions on matters of research, theory, policy and practice in the field of social work with children and their families. The Journal gives international definition to the discipline and practice of child and family social work.

MANUSCRIPT CATEGORIES AND REQUIREMENTS

Original Articles should normally be a maximum of 7000 words, including the abstract and any appendices, although shorter papers will be welcomed. References are not included in the 7000 word limit. The abstract should not exceed 200 words and it should be followed by six keywords.

The Editors also welcome the following scholarly papers:

Review These will be actively encouraged. Prospective authors should initially discuss their proposals with the Editor.

Spotlight This section publishes brief contributions (around 1000 words) on policy debates in different countries or short policy articles. Contributions are welcomed.

Special Issues From time to time the Editor may commission a special issue of the Journal which will take the form of a number of papers devoted to a particular theme.

Book Review

(i) Book reviews should be headed with the reviewer's name, in capitals. Beneath the reviewer's name, and ranged to the right, should come the full publication information (i.e., title in full, author, place, publisher, date of publication, edition statement, pages, special features [maps, color plates, etc.], price, and ISBN), for example:

The Peasantries of Europe: From the Fourteenth to the Eighteenth Centuries, by Tom Scott (ed.). London and New York: Longman. 1998. pp. xi+416. £ 44 (hb); £19.99 (pb). ISBN 0-582-10132-8 and 0-582-10131-X

(ii) The reviewer's institutional affiliation should appear (ranged to the left) as an unnumbered footnote on the first page of the review. Acknowledgements, if any, should also be made there.

Structure the book review as follows:

- One paragraph identifying the thesis, and whether the author achieves the stated purpose of the book.
- One or two paragraphs summarizing the book.
- One paragraph on the book's strengths.
- One paragraph on the book's weaknesses.
- One paragraph on your assessment of the book's strengths and weaknesses.

The word limit is 1000 words.

PREPARING YOUR SUBMISSION: FREE FORMAT SUBMISSION

Child & Family Social Work now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will

also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.

- The title page of the manuscript, including statements relating to our ethics and integrity policies:
- data availability statement
- funding statement
- conflict of interest disclosure
- ethics approval statement
- patient consent statement
- permission to reproduce material from other sources

Important: the journal operates a double-blind peer review policy. Please anonymise your manuscript and prepare a separate title page containing author details.

- Your co-author details, including affiliation and email address.
- An ORCID ID, freely available at https://orcid.org.

To submit, login at **https://wiley.atyponrex.com/journal/CFS** and create a new submission. Follow the submission steps as required and submit the manuscript.

FINAL SUBMISSION REQUIREMENTS

Parts of the Manuscript

Manuscripts can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file should be submitted in Microsoft Word (.doc or .docx) format.

Title page

The Title page should be uploaded under the designation 'title page'.

The title page should contain:

i. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
ii. A short running title of less than 40 characters
iii. The full names of the authors;
iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
v. Acknowledgments.

Authorship

Please refer to the journal's authorship policy the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

Main Text File

The Manuscript without title page should be uploaded under the designation 'main document'.

As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors.

The main text file should be presented in the following order:

i. Title, abstract and key words;
ii. Main text;
iii. References;
iv. Tables (each table complete with title and footnotes);
v. Figure legends;
vi. Appendices (if relevant).

Figures and supporting information should be supplied as separate files under the designation 'figures'

Abstract
Please provide an abstract of no more than 200 words.The abstract should be followed by up to six keywords.

References
References in published papers are formatted according to the Publication Manual of the American Psychological Association (6th edition). However, references may be submitted in any style or format, as long as it is consistent throughout the manuscript.

Tables
Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends
Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Figures
Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Color Figures. Figures submitted in color may be reproduced in color free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white.

Additional Files

Appendices
Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.

Supporting Information
Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

The following points provide general advice on formatting and style.

- **Language**: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality.
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

- **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.

Appendix E: University of Edinburgh Ethics Application and Approval

CPAUniversity of Edinburgh, School of Health in Social Science

RESEARCH ETHICS APPLICATION (REA)

The forms required when seeking ethical approval in the School of Health and Social Sciences have now been merged into this single electronic document. The sections you are required to complete will depend on the nature of your application. Please start to complete the form from the beginning and proceed as guided. **On completion the *entire* document should be submitted electronically to your section's ethics administrator using the email addresses detailed on the final page.**

Applications submitted without appropriate documentation will be returned.

Please indicate what sections of the SHSS Ethics forms completed herewith (✓):

Sections of Forms		Summary of 'Methods'
Level 1	**Level 2/3**	
✓		

FORM OVERVIEW	
SECTION	**COMPLETION**
Project registration form	Compulsory for all applications
Document checklist	Compulsory for all applications
Level 1 Self Audit form	To be completed for all research studies that are not subject to review by an external UK based ethical committee.
Level 2/3 ethical review form	To be completed when indicated by responses on the Level 1 form
Confidentiality and Handling of Data	To be completed by all applicants using personal data[1] as part of their research
Security Sensitive Material	To be completed by all applicants completing the Level 2/3 ethical review form.
Risks to and safety of researchers named in this application	To be completed by all applicants completing the Level 2/3 ethical review form.
Risks to and safety of participants	To be completed by all applicants completing the Level 2/3 ethical review form.
Research Design	To be completed by all applicants completing the Level 2/3 ethical review form.
Bringing the University into disrepute	To be completed by all applicants answering 'yes' to question SA3.

[1] Personal data is "any information relating to an identifiable person who can be directly or indirectly identified in particular by reference to an identifier". This includes structured recorded information about a living individual, that is identifiable directly or indirectly including by online identifiers.

PROJECT REGISTRATION FORM

This form is the first stage in applying for University ethical approval and should be completed prior to the commencement of any research project. Applications submitted without appropriate documentation will be returned.

Ethical approval is required for all projects by staff or students conducting research, or similar.
Applicants should familiarise themselves with the School's Research Ethics Policy prior to completion.

PR1 Name of Applicant: Emma Juster
PR2 Name of Supervisor[2]: Dr Azucena Guzman
PR3 Project Title: The relationships between self-compassion, mindfulness, mastery, carer burden and distress in middle aged and older kinship carers
PR4 Subject Area (section of school): Clinical Psychology
PR5 If student, type of assessed work that this application relates to: Thesis for Doctorate in Clinical Psychology
PR6 Planned date of project submission: May 2022
PR7 Date ethics application submitted: October 2020
PR8 (Date complete information submitted if different):
PR9 IRAS Approval Number if applicable:
The following to be completed by ethics administrator
PR10 ***Date of initial response to applicant:***
PR11 ***Date of final approval:***
PR12 ***Amendments Requested Date:***
PR13 ***Amendments Approved Date:***
PR14 ***Reviewer 1***
PR15 ***Reviewer 2*** ***Level 2/3 only***
DOCUMENTATION CHECKLIST

DC1 Does your research project require extraction or collection of data abroad? (✓)

✓	**No**	*If 'No' Skip to DC2*
	Yes	Local Ethical review needed, please confirm (✓) you have included an electronic attachment of: *application to ethical review panel in country of data collection (in English)* ***+*** *copy of letter of approval*

[2] Not applicable to staff members.

DC2 For the purposes of this research study, will you access identifiable[3] information on any NHS patient? (✓)

✓	**No**	*If 'No' Skip to DC3*
	Yes	Please confirm (✓) you have included an electronic attachment of: ***Caldicott Guardian*** *approval for use of NHS data or confirmation that it is not required*

DC3 Does the project require ethical review by an external UK committee e.g. NHS REC or Social Work?

✓	**No**	*If 'No' Skip to DC4*
	Yes	Please confirm (✓) you have included an electronic attachment of: *NHS REC (IRAS) /other application form + copy of letter of approval*

NOTE: If you have answered 'yes' you are ***not*** required to complete University ethical review forms. **Skip to DC6.**

DC4 Unless you answered 'yes' to DC3, you must also obtain ethical approval through the University of Edinburgh process. Please complete and submit the rest of this form (with 'Methods' summary).

DC5 Please list any additional documentation provided in support of your application (E.g. Disclosure, consent form, participant information, GP letters etc., Data Storage Plan)

Documentation Name These should reflect content	(✓)	**Documentation Name**	(✓)
Participant Information Sheet- Study 1	✓	**Study Debrief Sheet**	✓
Participant Consent Form-Study 1	✓	**Demographic Questionnaire**	✓
Study Flyer	✓		

DC6 Signatures

_____Emma Juster____	____E.Juster_____	_06/10/2020____
Applicant's Name	Applicant's Signature	Date signed
___Dr Azucena Guzman__		12/07/2021____
Supervisor[4] Name	Supervisor's Signature	Date signed

Please return an electronic copy of your UoE HSS Ethics Application Form (in its entirety) to your Subject Area Ethics Administrator, accompanied by electronic copies of additional documents indicated above. We do not accept paper documentation; please scan all documents into electronic formats. Please keep a copy of all documentation for your records.

SELF AUDIT FORM: LEVEL 1

[3] 'Identifiable information' refers to information that would allow you to know, or be able to deduce, the identity of a patient. The most common examples of this would be accessing medical records or similar, or accessing a database that includes patients' names.

[4] Not required for staff applications.

The audit is to be conducted by all staff and students conducting any type of empirical investigation, including research, audit or service evaluation.

The form should be completed by the principal investigator and, with the exception of staff, signed by a University supervisor.

SA1 Primary Research Question:

Please tick	What type of research are you planning to do?
	Study of a novel intervention or randomised clinical trial to compare interventions in clinical practice
✓	Study utilising questionnaires, interviews or measures, including auto-ethnographic data.
	Study limited to working with routinely collected clinical data.
	Meta-analysis or systematic review.
	Research database containing non-identifiable information.

SA2 Please provide a brief summary of your proposed study. Our interest is in areas of your methodology where ethical issues may arise so please focus your detail on areas such as recruitment, consent, describing your participants and the nature of their involvement, and data handling.

Project Summary:

Research Questions

1. Does carer burden predict distress in a population of middle aged and older kinship carers?
2. Is self-compassion associated with distress in this population?
3. Is mindfulness associated with distress in this population?
4. Do self-compassion and mindfulness moderate the relationship between carer burden and distress?
5. Does mastery mediate the relationship between carer burden and distress?
6. What are the attitudes to psychological help-seeking in this population?

Design

This study will be cross-sectional in nature with all data collected through online quantitate questionnaires. It will recruit middle aged and older kinship carers from the general population. Participants will be invited to complete six questionnaires, measuring psychological distress (anxiety, depression and stress), carer burden, self-compassion, mindfulness, mastery and attitudes to seeking psychological help. A series of correlation and regression analyses will be implemented in order to answer the research questions posed by the current study.

Participants

Participants will be kinship carers over the age of 55. A kinship carer is defined as an individual who is looking after a child who is not their own fulltime, taking on the role of the child's parent. This may be a informal arrangement made between family members or the child may be "looked after" by the local

authority and officially placed with their relative (Grandparents plus, 2020). Participants must currently caring for a child aged between 0-21 years.

Procedure

Participants will be recruited through online, recruitment pathways, explained in more detail below and summarised in Figure 1.

Social media recruitment
The Qualtricts survey management website will be used to host the questionnaires. Participants will be able to access the questionnaires via a link which will be distributed by the methods described. The study information and consent form will be contained within the Qualtrics platform, as well as the questionnaires and debrief information. The Qualtrics link will be distributed through social media using facebook and twitter. The study will be advertised on the local NHS health board facebook page, with potential participants being able to follow the link to the study. The lead researcher will also ask each NHS locality to advertise the study on their health and social care pages. Links had been made between the local health board and the local area kinship carer representative prior to COVID-19. The researcher will approach the local area kindship carer representative and ask them to circulate the study information and link via kinship carer support groups on social media. In relation to twitter, the Qualtrics link will be tweeted to local and national organisations which support kinship carers, such as Kindred Spirits, Kinship and Children 1st. The link will also be tweeted to organisations that support carers, such as Carers UK, with the aim of reaching older individuals who may be informal kinship carers.

Support Groups
All of the Kinship Care support groups will be contacted across Scotland and informed of the study. They will be asked to advertise the study and circulate Qualtrics link to their members. The lead researcher will ask to attend any virtual meetings to advertise the study and to circulate the Qualtrics link.

Snowball sampling will be used to aid recruitment with participants encouraged to send the Qualtrics link to other kinship carers after completion of the study. It is hoped that this will reach potential participants who might not be otherwise made aware of the study, for example those who are not active on social media. Posters and online messages promoting the study will encourage people who know of kinship carers to make them aware of the study and help them access the online questionnaires, if required. Paper copies of the questionnaires can also be requested from the lead researcher if the participant would prefer.

All participants will be given the options to be entered into a prize draw to win one of four £25 amazon vouchers. I participants wish to enter they can enter their email address or telephone number at the end of the study. The draw will take place at the end of the recruitment period.

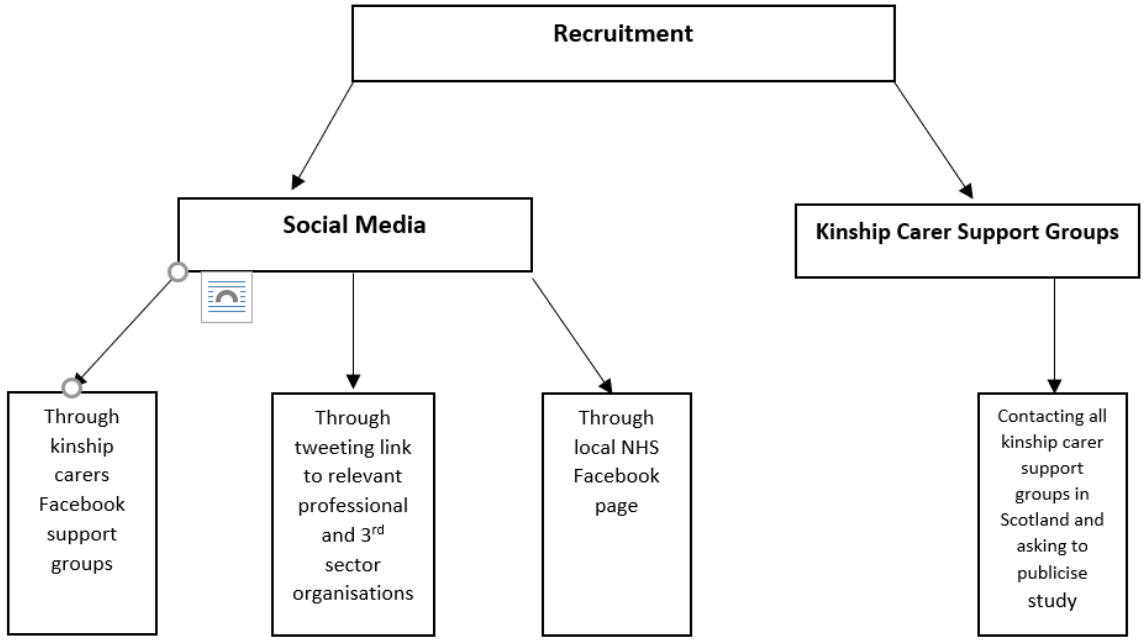

Figure 1: Summary of recruitment methods

Data

A demographic questionnaire will be used to collect gender, age, location (city), ethnicity, current occupation, number of children currently looked after and their ages, length of time as a kinship carer and reason for becoming a kinship carer (this will be an optional question to reduce potential distress or shame participants may feel answering it).

The following quantitative questionnaires will be used:

Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995)
This measure is a shortened version of the original 42-item measure of distress, the DASS. It is used to assess levels of distress with three different subscales: depression, anxiety and stress. It is composed of 21 items scored on a four-point scale ranging from "did not apply to me at all" to "applied to me very much or most of the time". Higher scores indicate higher levels of distress. Chronbach's alpha for the subscales range from 0.79 to 0.84.
Example item: I found it difficult to relax.

Zarit Burden Interview- short version (ZBI- short version; Bedard et al., 2001)
The ZBI-short version is a 12-item version of the 22-item questionnaire originally developed to measure burden in caregivers of people with dementia. It asks participants to choose one of five responses to reflect how they feel about statements ranging from "never to "nearly always". The short version correlates excellently with the original questionnaire (r=.92-.97) and displays good validity and reliability (α=.92). Versions of the original ZBI have been used with other caregiving populations, including grandparent caregivers (Conway et al., 2010), by changing the wording to reflect the population. In the Conway et al. study reliability of the adapted ZBI was high (α= .93). As Bedard et al. (2001) conclude that the ZBI-short version retains the same properties as the original and produces identical results, this study will use an the ZBI-short version, changing the wording to reflect kinship carers.

Example item: Do you fee stressed between caring for your relative and trying to meet other responsibilities for your family or work?

The Self-Compassion Scale- Short Form (SCS-SF; Raes et al., 2011)
This measure is an economical alternative to the 26-item Self-Compassion Scale (Neff, 2003). The SCS-SF consists of 12 items, each rated on a five-point scale from "almost never" to "almost always". Total scores on the SCS-SF have been found to correlate highly (.98) with the 26-item version. Furthermore, it has been shown to be comparably reliable and have the same factorial structure as the original scale. The SCS-SF has good internal consistency (α=.86), with a test-retest reliability of .71.
Example item: When I'm going through a very hard time, I give myself the caring and tenderness I need.

The Mindful Attention Awareness Scale (MAAS; Brown & Ryan 2003)
The MAAS is a single-factor mindfulness measure composed of 15 items that describe ways in which a person may exhibit the absence of mindfulness, such as inattentiveness or states of automatic pilot. Respondents rate each item's frequency on a six-point Likert-type scale ranging from 1 (almost always) to 6 (almost never), and higher scores are associated with greater mindfulness. The measure has demonstrated good internal consistency (α= .89) withing a range of populations, including nonclinical samples (Brown & Ryan 2003).
Example item: I find myself doing things without paying attention

*The Global Mastery Scale (*Pearlin et al., 1990)
Mastery can be described as an individual's view of their capability to deal with, and have control over, difficulties in their life as they arise (Pearlin et al., 1990). The Global Mastery Scale consists of eight items which relate to the overall control individuals feel they have over their life and their future. Each item is rated on a four-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). The scale has good internal consistency (α= .88)
Example item: I have little control over the things that happen to me

Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPH; Fischer & Farina, 1995)
The ATSPPH is a 10-item questionnaire used to measure attitudes towards seeking professional help for psychological problems. are asked to rate each item on a four-point scale from "disagree" to "agree". The ATSPPH shows good internal consistency (α= .86), with satisfactory test-retest reliability (r=.80). A higher score on this measure indicates more favorable attitudes to seeking psychological help, with a greater likelihood that help will be sought.
Example item: There is something admirable in the attitude of a person who is willing to cope with his or her conflicts and fears without resorting to professional help.

Permission for using the measures will be sought by contacting the authors.

Approximate time taken to complete the measures: 20mins (based on two individuals over 55 years completing the questionnaires)

Data Storage
The data collected online through the Qualtrics survey management website will be downloaded and stored in an Excel spreadsheet. This will be stored in an encrypted password protected file on the

University of Edinburgh's Datastore. Identifiable data (i.e. participant email addresses) will be stored separately to the questionnaire data. Identifiable information will be kept for 1 year and anonymous da will be kept for 5 years, before being destroyed. Access to all study data will only be by the lead researc and their supervisor(s).

If participants wish they can be entered into a prize draw for the chance to win one of four £25 amazon vouchers as a thank you for their participation. Participants will be asked to leave their email address at the end of the study, should they wish to enter the prize draw. These email addresses will be stored securely for 1 year in an excel sheet, separate from the study data, in an encrypted password protected file on the University of Edinburgh's Datastore. They will be destroyed after 1 year.

Please circle your answer as appropriate:

ETHICAL ISSUES			
SA 3	Bringing the University into disrepute Is there any aspect of the proposed research which might bring the University into disrepute? For example, could any aspect of the research be considered controversial or prejudiced?	*No*	***YES***
SA 4	**Protection of research subject confidentiality** *Will you make every effort to protect research subject confidentiality by conforming to the University of Edinburgh's guidance on data security, protection and confidentiality as specified in:* www.ed.ac.uk/information-services/research-support/data-library/research-data-mgmt *For example, there are mutually understood agreements about:* (a) non-attribution of individual responses; (b) Individuals, and organisations where necessary, being anonymised in stored data, publications and presentations; (c) publication and feedback to participants and collaborators; (d) With respect to auto-ethnographic work it is recognised that the subject's anonymity cannot be maintained but the confidentiality of significant others must be addressed.	***NO***	*Yes*

The legal basis for all academic research using personal data is Article 6(1)(e) 'public task of the University', not consent. Please ensure that you do not rely on consent for the actual processing of research data.			
SA 5	**Data protection and consent to participate** *Will you make every effort to ensure the confidentiality of any data arising from the project by complying with* the University of Edinburgh's Data Management procedures (see http://www.ed.ac.uk/information-services/research-support/data-library/research-data-mgmt). For example (a) Ensuring any participants recruited consent to their data being collected, stored, archived and destroyed as appropriate; (c) Ensuring identifying information[5], (e.g. consent forms) is held separately from data and is only accessible by the chief investigator and their supervisors; (e) Ensuring there are no other special issues arising regarding confidentiality/consent. (f) Ensuring that where NHS data is being accessed Caldicott Guardian approval has been obtained. **IT IS NECESSARY TO GIVE THE HEAD OF SCHOOL'S NAME AS THE CONTACT PERSON IN CASE OF ANY COMPLAINT** **PLEASE MAKE SURE THAT THIS LINK IS PROVIDED on any Information sheet/consent form:** **(http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf)**	***NO***	*Yes*
SA 6	**Duty to disseminate research findings** Are there issues which will prevent all participants and relevant stakeholders having access to a clear, understandable and accurate summary of the research findings should they wish?	*No*	***YES***
SA 7	**Moral issues and Researcher/Institutional Conflicts of Interest** *Are there any SPECIAL MORAL ISSUES/CONFLICTS OF INTEREST?* Examples include, but are not limited to: (a) Where the purposes of research are concealed; (b) Where respondents are unable to provide informed consent (c) Where there is financial or non-financial benefit for *anyone* involved in the research, or for their relative or friend. (d) Where research findings could impinge negatively or differentially upon participants or stakeholders (for example when selecting an unrepresentative sample of a larger population). (e) Where there is a dual relationship between the researcher and subject? E.g. where the researcher is also the subject's practitioner or clinician. (f) Where research involves covert surveillance or covert data collection. (g) Where routinely collected data is used for research alongside novel data. **NOVEL DATA COLLECTION SHOULD NOT BE CONFLATED WITH ROUTINELY COLLECTED DATA. WHERE BOTH ARE BEING USED THIS NEEDS TO BE MADE CLEAR IN ANY COVERING LETTER,**	*No*	***YES***

	PARTICIPANT INFORMATION SHEET AND CONSENT FORM IN ORDER FOR INFORMED CONSENT TO BE POSSIBLE.		
SA 8	**Potential physical or psychological harm, discomfort or stress** Is there any foreseeable potential for: (a) significant psychological harm or stress for participants (b) significant physical harm or discomfort for participants? (c) significant risk to the researcher? Examples of issues/ topics that have the potential to cause psychological harm, discomfort or distress and should lead you to answer 'yes' to this question include, but are not limited to: *Relationship breakdown; bullying; bereavement; mental health difficulties; trauma / PTSD; Violence or sexual violence; physical, sexual or emotional abuse in either children or adults; feedback of results from the project's assessments.*	*No*	***YES***
SA 9	**Vulnerable participants** Will you be ***recruiting*** any participants or interviewees who could be considered vulnerable? Examples of vulnerable groups, the inclusion of which should lead you to answer yes to this question include, but are not limited to: Clients or patients of either the researcher OR the person recruiting subjects; Children & young people; people who are in custody or care for example, offenders, looked after children or nursing home resident; persons with mental health difficulties including those accessing self-help groups; auto-ethnographic researchers examining distressing topics.	*No*	***YES***

[5] 'Identifiable information' refers to information that would allow you to know, or be able to deduce, the identity of a patient. The most common examples of this would be accessing medical records or similar, or accessing a database that includes patients' names.

Level 1 Assessment outcome:

SA10 Have you circled any answers in <u>BOLD</u> typescript? Please tick as appropriate

No ☒

(i) Your responses on the completed self-audit confirm the ABSENCE OF REASONABLY FORESEEABLE ETHICAL RISKS.
(ii) Please now read the guidance below and provide the required signatures.
(iii) You are NOT REQUIRED to complete the Level 2/3 sections of this form.
(iv) Please submit the UoE HSS Ethics Application Form electronic document (in its entirety) along with ALL additional required documentation, failure to do so will mean that your form is returned to you.

Yes ☐

a. Your responses on the completed self-audit indicate that we require further information to consider your application.
b. Read the Guidance below and provide the required signatures.
(ii) You **ARE REQUIRED** to complete the Level 2/3 application form.
(III) Please continue to the next part of this document where you will find the level 2/3/4 form

Subsequent to submission of this form, <u>any</u> alterations in the proposed methodology of the project should be reviewed by both the applicant and their supervisor. If the change to methodology results in a change to any answer on the form, then a resubmission to the Ethics subgroup is required.

The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

ALL forms should be submitted in electronic format. Digital signatures or scanned in originals are acceptable. The applicant should keep a copy of all forms for inclusion in their thesis.

__Emma Juster_____		__6/10/2020___
Applicant's Name	Applicant's Signature	Date

____	Dr Azucena Guzman_____	___1207/2021___
*Supervisor Signature[6]	Supervisor Name	Date

*NOTE to Supervisor: Ethical review will be based only on the information contained in this form. If countersigning this check-list as truly warranting all 'No' answers, you are taking responsibility, on behalf of the HSS and UoE, that the research proposed truly poses no ethical risks.

[6] Not required for staff applications

CONFIDENTIALITY AND HANDLING OF DATA

BEFORE COMPLETING THIS SECTION, PLEASE MAKE REFERENCE TO THE

UNIVERSITY OF EDINBURGH'S DATA PROTECTION POLICY AND RESEARCH DATA PROTECTION GUIDANCE

ER1: What information about participants'/subjects' data will you collect and use? Please specify if any personal data will be collected.

A demographic questionnaire will be used to collect participant's gender, age, location (city), ethnicity, current occupation, number of children currently looked after and their ages, length of time as a kinship carer and reason for becoming a kinship carer (this will be an optional question to reduce potential distress or shame participants may feel answering it).

Participants will be asked to complete the following questionnaires:

Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995)
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Example item: There is something admirable in the attitude of a person who is willing to cope with his or her conflicts and fears without resorting to professional help.

In addition to this participants will provide their email address if they wish to participate in the prize draw.

ER2: Will you collect or use NHS data?

If you are collecting or using NHS data you may require sponsorship and/or Caldicott Approval.
Please refer to the ACCORD (Academic and Clinical Central Office for Research and Development) website for more information.

No

ER3: Who will have access to the raw data?

Only the lead researcher and their supervisor will have access to the raw data.

ER4: What training will staff who have access to the data receive on their responsibilities for its safe handling? All staff must complete the following mandatory Data Protection training available through the self-enrolment page on Learn:

- **Data Protection for Research (DP Training Research)**
- **Data Protection Training**

All staff will have undertaken the mandatory training required for data protection. In addition, the lead researcher has completed the MANTRA Research Data Management Training and the NIHR Introduction to Good Clinical Practice Course.

The legal basis for all academic research using personal data is Article 6(1)(e) 'public task of the University', not consent. Please ensure that you do not rely on consent for the actual processing of research data.

ER5: Will the information include special categories of personal data?
These include:

- **health data**
- **data relating to race or ethnicity**
- **to political opinions or religious beliefs**
- **trade union membership**
- **criminal convictions**
- **sexual orientations**
- **genetic data**
- **biometric data**

☒ Yes
☐ No

If yes, go to ER7, if no, go to ER9.

Ensure that your legal basis for using one or more of these special categories of personal data in your research is Article 9(2)(j) – processing is necessary for research purposes.

ER6: How will the confidentiality of the data, including the identity of participants, be ensured? Is there a strategy in place to replace disclosive identifiers of an individual or entity from the data? Explain what safeguards e.g. technical or organisational you have in place, such as:

- Compliance with the minimisation principle – use only the absolute minimum of personal data required for your purpose
- Anonymising personal data if you can
- If you cannot anonymise, wherever possible, pseudonymise all personal data
- Storing the data securely

Confidentiality of participants will be ensured by storing the data securely. The data collected online through the Qualtrics online survey management website will be downloaded and stored in an Excel spreadsheet. This will be store in an encrypted password protected file on the University of Edinburgh's Datastore. Identifiable data (i.e. participant email addresses) will be stored separately to the questionnaire data. Access to all study data will only be by the lead research and their supervisor(s).

ER7: Do the systems you will be using to store your data comply with the University's Information Security Policy?

(see http://www.ed.ac.uk/information-services/about/policies-and-regulations/security-policies/security-policy)

YES/NO **If NO, explain why not.**

ER8: The new legal basis for conducting research is 'public task of the University'. For this reason researchers need to demonstrate how their research is in the public interest. Please indicate how your research has been demonstrated to be in the public interest using the options below.

☒ Your research is proportionate

☐ Your research is subject to a governance framework

☐ Your research has undergone review by a Research Ethics Committee (does not have to be a European REC)

☐ Your research has been peer reviewed by a funder

☐ Confidentiality Advisory Group (CAG) recommendation for support in England and Wales or support by the Public Benefit and Privacy Panel (PBPP) for Health and Social Care in Scotland

☐ Other (please indicate).

ER9: You must consult your collaborators before answering the following questions. It is essential that you identify and list all risks to the privacy of research participants. You will then need to consider the likelihood of the risks manifesting and the severity of harm if they do.

Risk	**Likelihood of risk manifesting**			**Severity of harm**		
	Remote	**Possible**	**Probable**	**Minimal**	**Significant**	**Severe**
Identifiable due to data linkage	☐	☒	☐	☒	☐	☐
Identifiable due to low participant numbers	☐	☒	☐	☒	☐	☐
Identifiable due to geographical location	☐	☒	☐	☒	☐	☐
Identifiable due to transfer of data	☒	☐	☐	☒	☐	☐
Identifiable due to access of data	☒	☐	☐	☒	☐	☐
Insert more rows as appropriate	☐	☐	☐	☐	☐	☐

ER10: Please identify measures you could take to reduce or eliminate the risks identified as possible/significant or probable/severe?

ER11: Will information containing personal, identifiable data be transferred to, shared with, supported by, or otherwise available to third parties outside the University?

☐ Yes
☒ No

If yes go to ER12 if no go to ER13

ER12: Please explain why this necessary and how the transfer of the information will be made secure. If the third party is based outside the European Economic Area please obtain guidance from the Data Protection Officer.

ER13: Other than the use by third parties under section 5.7, will the data be used, accessed or stored away from University premises?

☒ Yes
☐ No

If yes go to ER14 and no go to ER15

ER14: Describe the arrangements you have put in place to safeguard the data from accidental or deliberate access, amendment or deletion when it is not on University premises, including when it is in transit, and (where applicable) it is transferred outside the EEA.

Not applicable- all data will be collected and stored electronically. Electronic data will be stored securely.

ER15: Will feedback of findings be given to your research project participants?

☒ Yes
☐ No

ER16: Describe the physical and security arrangements you will put in place for the data.

Electronic data will be stored in an encrypted password protected file on the University of Edinburgh's datastore. Only the lead researcher and their supervisor(s) will know the password.

ER17: How do you intend the results of your research project to be used?

The data collected will be used as part of the lead researcher's thesis as part of their Doctorate in Clinical Psychology. T results of the study will be written up for publication in a peer reviewed journal. Results of the study may also be disseminated at conferences and/or by poster presentations.

ER18: Does your project involve using secondary data?

☐ Yes
☒ No

ER19: Is this reuse compatible with what the data subjects were originally told about the use of their data? (e.g. were they told that it would be destroyed at the end of the study?)

☐ Yes
☐ No

ER20: Is it likely that someone could be identified from this data?
It is extremely difficult to make something totally anonymous, so even with secondary data there may be a need to apply security and access restrictions to it.

☐ Yes
☒ No

ER21: Specify where the data files/audio/videotapes etc. will be retained after the study, how long they will be retained and how they eventually will be disposed of?

N/A

Please note: Research data can be stored indefinitely as long as it is stored securely. For storage guidance please refer to LINK TO DATAVAULT/UNIVERITY STORAGE INFORMATION

For more information regarding data linkage in evaluating interventions for the benefit of the population's health, please see: http://www.gov.scot/Topics/Statistics/datalinkageframework

Your application at this level is likely to require additional documentation, for example a Data Storage Plan, consent forms or participant information sheets. Please return to the Documentation Checklist on page 2 to list your supporting documentation.

LEVEL 2/3 ETHICAL REVIEW

Complete only if indicated in the conclusion of your Level 1 form. Applications will be monitored and audited to ensure the School Ethics Policy and procedures are complied with and applicants contacted in cases where there are concerns or queries. Research must not proceed before ethical approval has been granted. For this reason it is particularly important that applications are submitted well in advance of any required date of approval.

If the answer to any of the questions below is 'yes' please elaborate and give details of how the issue will be addressed to ensure ethical standards are maintained. The response boxes will expand as you complete them. Forms not containing sufficient detail will be returned incurring delay.

SECURITY-SENSITIVE MATERIAL

ER22 Does your research fit into any of the following security-sensitive categories? If so, indicate which.

YES/**NO** **Commissioned by the military**

YES/**NO** **Commissioned under an EU security call**

YES/**NO** **Involve the acquisition of security clearances**

YES/**NO** **Concern groups which may be construed as terrorist or extremist**

IF YOU HAVE ANSWERED YES TO ANY OF THESE CONTINUE TO ER23. IF YOU HAVE ANSWERED NO TO ALL OF THESE QUESTIONS MOVE TO ER28.

ER23 The Terrorism Act (2006) outlaws the dissemination of records, statements and other documents that can be interpreted as promoting or endorsing terrorist acts.

YES/**NO** Does your research involve the storage on a computer of such records, statements and other documents?

YES/**NO** Might your research involve the electronic transmission (e.g. as an email attachment) of records or statements?

IF YOU ANSWERED YES TO ANY OF THESE YOU ARE ADVISED TO STORE THE RELEVANT RECORDS OR STATEMENTS ELECTRONICALLY ON A SECURE UNIVERSITY FILE STORE. THE SAME APPLIES TO PAPER DOCUMENTS WITH THE SAME SORT OF CONTENT. THESE SHOULD BE SCANNED AND UPLOADED.

ACCESS TO THIS FILE STORE WILL BE PROTECTED BY A PASSWORD UNIQUE TO YOU AND YOUR SCHOOL RESEARCH ETHICS OFFICER. PLEASE INDICATE THAT YOU AGREE TO STORE ALL DOCUMENTS RELEVANT TO THESE QUESTIONS ON THAT FILE STORE:

YES/NO

ER24 Please indicate that you agree not to transmit electronically to any third party documents in the document store:

YES/NO

ER25 Will your research involve visits to websites that might be associated with extreme or terrorist organisations?

YES/**NO**

ER26 If you answer YES to ER18 you are advised that such sites may be subject to surveillance by the police. Accessing those sites from University IP addresses might lead to police enquiries. Please acknowledge that you understand this risk:

YES/NO

ER27 By submitting to the research ethics process, you accept that your School Research Ethics Officer and the convenor of the University's Compliance Group will have access to a list of titles of documents (but not the content of documents) in your document store. Please acknowledge that you accept this.

YES/NO

Countersigned by supervisor/manager:

Name:

Date:

RISKS TO, AND SAFETY OF, RESEARCHERS NAMED IN THIS APPLICATION

ER28: Do any of those conducting the research named above need appropriate training to enable them to conduct the proposed research safely and in accordance with the ethical principles set out by the College?

YES / **NO**

ER29: Are any of the researchers likely to be sent or go to any areas where their safety may be compromised, or they may need support to deal with difficult issues?

YES / **NO**

ER30: Could researchers have any conflicts of interest?

YES / **NO**

RISKS TO, AND SAFETY OF, PARTICIPANTS

ER31: Are any of your participants children or protected adults (protected adults are those in receipt of registered care, health, community care or welfare services. Anyone who will have contact with children or protected adults requires approval from Disclosure Scotland at http://www.disclosurescotland.co.uk/

Do any of the researchers taking part in this study require Disclosure Scotland approval? (√)

Not applicable	
Relevant researcher/s has current Disclosure Scotland approval through a current NHS employment contract	**√**
Yes *(ethical approval will be subject to documentation confirming Disclosure Scotland approval with this form)*	

ER32: Could the research induce any psychological stress or discomfort?

YES / **NO**

ER33: Does the research involve any physically invasive or potentially physically harmful procedures?

YES / **NO**

ER34: Could this research adversely affect participants in any other way?

YES / **NO**

RESEARCH DESIGN

ER35: Does the research involves living human subjects specifically recruited for this research project ***If 'yes' please complete the rest of this section.***
YES / NO
ER36: How many participants will be involved in the study?
Around 80 participants
ER37: What criteria will be used in deciding on inclusion/exclusion of participants?
Inclusion criteria: -Aged 55 or older, - Able to write and speak English - Meets definition of kinship carer (i.e., relative or family friend who is looking after a child full-time as their parents aren't able to care for them) -Currently is caring for a child in a kinship role who is aged 0-21 years and who lives at home with them. -Able to complete questionnaires online *Exclusion criteria* - Unable to provide consent to participate (e.g. due to cognitive impairment such as dementia) - Currently suicidal or acutely mentally unwell
ER38: How will the sample be recruited? (E.g. posters, letters, a direct approach- specify by whom.)

Participants will be recruited through online, recruitment pathways, explained in more detail below and summarised in Figure 1.

Social media recruitment
The Qualtricts survey management website will be used to host the questionnaires. Participants will be able to access the questionnaires via a link which will be distributed by the methods described. The study information and consent form will be contained within the Qualtrics platform, as well as the questionnaires and debrief information. The Qualtrics link will be distributed through social media using facebook and twitter. The study will be advertised on the local NHS health board facebook page, with potential participants being able to follow the link to the study. The lead researcher will also ask each NHS locality to advertise the study on their health and social care pages. Links had been made between the local health board and the local area kinship carer representative prior to COVID-19. The researcher will approach the local area kindship carer representative and ask them to circulate the study information and link via kinship carer support groups on social media. In relation to twitter, the Qualtrics link will be tweeted to local and national organisations which support kinship carers, such as Kindred Spirits, Kinship and Children 1st. The link will also be tweeted to organisations that support carers, such as Carers UK, with the aim of reaching older individuals who may be informal kinship carers.

Support Groups
All of the Kinship Care support groups will be contacted across Scotland and informed of the study. They will be asked to advertise the study and circulate Qualtrics link to their members. The lead researcher will ask to attend any virtual meetings to advertise the study and to circulate the Qualtrics link.

Snowball sampling will be used to aid recruitment with participants encouraged to send the Qualtrics link to other kinship carers after completion of the study. It is hoped that this will reach potential participants who might not be otherwise made aware of the study, for example those who are not active on social media. Posters and online messages promoting the study will encourage people who know of grandparent kinship carers to make them aware of the study and help them access the online questionnaires, if required. Paper copies of the questionnaires can also be requested from the lead researcher if the participant would prefer.

All participants will be given the options to be entered into a prize draw to win one of four £25 amazon vouchers. I participants wish to enter they can enter their email address at the end of the study. The draw will take place at the end of the recruitment period.

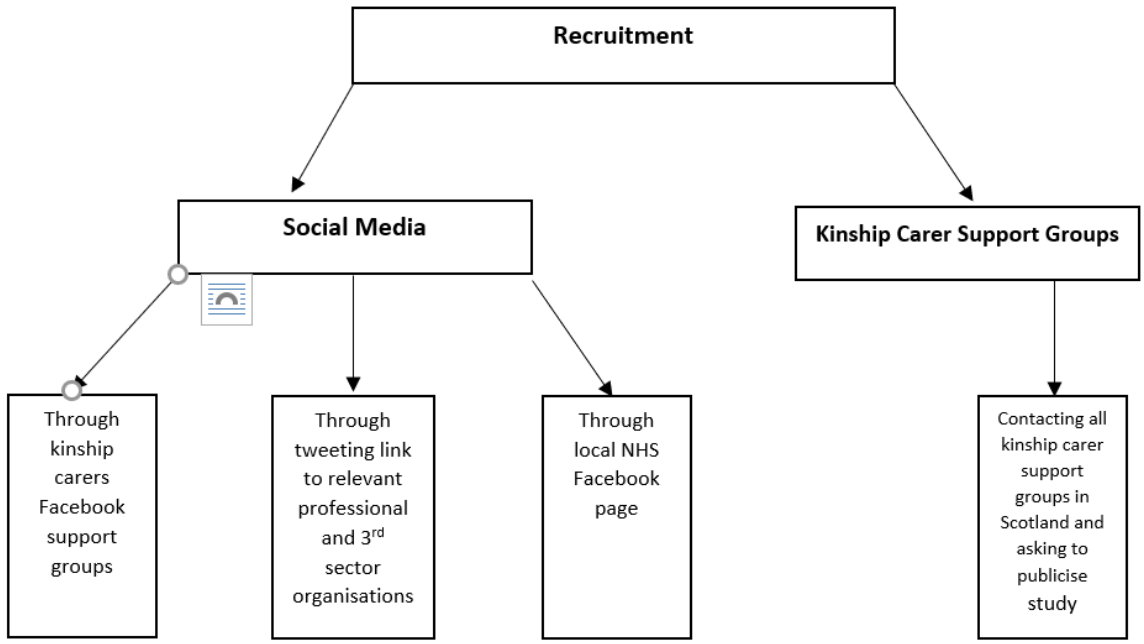

Figure 1: Summary of recruitment methods

ER39: Will the study involve groups or individuals who are in custody or care, such as students at school, self-help groups, or residents of nursing home?

YES / **NO**

ER40: Will there be a control group?

YES / **NO**

ER41: What information will be provided to participants prior to their consent? (e.g. information leaflet, briefing session)

Information regarding the study, why they have been asked to participate and how to take part is provided one the Qualtrics platform. Participants will be directed to this information when they follow the study's online link.

ER42: Participants have a right to withdraw from the study at any time. Please tick to confirm that participants will be advised of their rights, including the right to continue receiving services if they withdraw from the study.

YES / NO

ER43: Will it be necessary for participants to take part in the study without their knowledge and consent? (e.g. covert observation of people in non-public places)

YES / **NO**

ER44: Where consent is obtained, what steps will be taken to ensure that a written record is maintained?

Participants will be required to tick a box to confirm that they have read the information sheet, give their consent to participate and can withdraw at any time. If they do not tick this box they will not be able to proceed onto the next page of the online survey and instead will be directed to the debrief page.

ER45: In the case of participants whose first language is not English, what arrangements are being made to ensure informed consent?
It is made clear in the information sheet that participants must be able to read and understand English in order to participate in the study.
ER46: Will participants receive any financial or other benefit from their participation?
YES / NO
ER47: Are any of the participants likely to be particularly vulnerable, such as elderly or disabled people, adults with incapacity, your own students, members of ethnic minorities, or in a professional or client relationship with the researcher?
YES / **NO**
ER48: Will any of the participants be under 16 years of age?
YES / **NO**
ER49: Will any of the participants be interviewed in situations which will compromise their ability to give informed consent, such as in prison, residential care, or the care of the local authority?
YES / **NO**

BRINGING THE UNIVERSITY INTO DISREPUTE
ER50: If on the level one form you have answered YES that some aspect of the proposed research "might bring the University into disrepute", please elaborate alongside how this might arise, and what steps will be taken by the researcher to mitigate and/or manage this, to minimise adverse consequences to the University.
N/A

Subsequent to submission of this form, **both the applicant and their supervisor should review any alterations in the proposed methodology of the project.** If the change to methodology results in a change to any answer on the form, then a resubmission to the Ethics subgroup is **required.**

The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

ALL forms should be submitted in electronic format. Digital signatures or scanned in originals are acceptable. The applicant should keep a copy of all forms for inclusion in their thesis.

___Emma Juster_____	___E.Juster_____	__6/11/2020__
Applicant's Name	Applicant's Signature	Date
_____	___Dr Azucena Guzma_____	__12/07/2021_____
*Supervisor Signature[7]	Supervisor Name	Date

*NOTE to Supervisor: Ethical review will be based only on the information contained in this form. If countersigning this check-list as truly warranting all 'No' answers, you are taking responsibility, on behalf of the HSS and UoE, that the research proposed truly poses no ethical risks.

ER51: ISSUES ARISING FROM THE PROPOSAL

[7] Not required for staff applications

Reviewer comments

Missing on campus or off campus COVID risk assessment form (obtain a copy of this from your supervisor and please complete it).

SA2 – Recruitment needs to be re-thought given the pandemic. I can see that links had been made prior to COVID but given that the GPs and local health services are already strained is it ethical to still pursue these routes for the research question?

Also mention the use of fliers/collecting actual paperwork is strongly discouraged given the current pandemic. The risk of exchanging the documents, storing the documents etc heightens the risk of infection. Is there a way to rely on online methods of recruitment only? In relation to this in ER 6 you mention paper questionnaires – how will these be given out and collected during a time of heightened covid risk? Can't the whole study be carried out offline?

Why is the participant information sheet separate from the online questionnaires? Can't you set the questionnaire up to include the consent screen and participant info screen so that interested parties can read the online info sheet and confirm they are happy to take part? This will remove the need to send permission slips etc.

At the end you mention that participants will be invited to provide their email address for any future research study. You can't collect identifiable information like email addresses because you 'may' use this in future (principle of minimisation) – you can only collect the minimal data required to address your research questions you can't just collect data that you *may* use in the future. There is mention of email addresses being collected and then deleted in the participant information sheet then the use of email addresses being entered into a prize draw in the debrief but can't see mention of prize draw in the application – can you please clarify exactly what is happening with email addresses in this study and what they are being used for?

How will participants find out about the results/findings of the study? Should think about how this can be done even if participants do not wish to provide their email address.

You say participants will be able to withdraw at any point can you confirm that the JISC online questionnaire system has been set up so that when a participant stops answering questions that none of their answers will be recorded? If this can't be done then must be clear (in participant info screen etc) that if they begin the questionnaire their answers will be recorded and stored (and therefore may be used) even if they stop the questionnaire.

Linked to above if the participants don't give their address and there is no identifiable data provided how will you be able to withdraw someone from the questionnaire if they get in touch with you?

Signature:

Position: Lecturer in Applied Psychology

Date: 22.01.21

ER52 APPLICANT'S RESPONSE (If required)

Reviewers Comment	Applicant's Response
Missing on campus or off campus COVID risk assessment form (obtain a copy of this from your supervisor and please complete it).	Azu has requested that a copy of this form be sent to her however we are yet to obtain one. Please could a copy of this form be sent to myself and Azu.
SA2 – Recruitment needs to be re-thought given the pandemic. I can see that links had been made prior to COVID but given that the GPs and local health services are already strained is it ethical to still pursue these routes for the research question?	Please see section SA2 for changes highlighted in yellow. I have removed the community recruitment arm so all recruitment will be online.
Also mention the use of fliers/collecting actual paperwork is strongly discouraged given the current pandemic. The risk of exchanging the documents, storing the documents etc heightens the risk of infection. Is there a way to rely on online methods of recruitment only? In relation to this in ER 6 you mention paper questionnaires – how will these be given out and collected during a time of heightened covid risk? Can't the whole study be carried out offline?	The form has been amended and the study will now be online only, taking away the need for paper copies of questionnaires. This also negates the need for the storage of paper questionnaires commented on in page 6.
Why is the participant information sheet separate from the online questionnaires? Can't you set the questionnaire up to include the consent screen and participant info screen so that interested parties can read the online info sheet and confirm they are happy to take part? This will remove the need to send permission slips etc.	I have amended this throughout the form. The consent form and information sheet will be integrated into the Qualtrics system so that potential participants access all components of the study through the study link.
At the end you mention that participants will be invited to provide their email address for any future research study. You can't collect identifiable information like email addresses because you 'may' use this in future (principle of minimisation) – you can only collect the minimal data required to address your research questions you can't just collect data that you *may* use in the future. There is mention of email addresses being collected and then deleted in the participant information sheet then the use of email addresses being entered into a prize draw in the debrief but can't see mention of prize draw in the application – can you please clarify exactly what is happening with email addresses in this study and what they are being used for?	I have removed the part about collecting emails to contact participants about future research. I have inserted a section on pg. 6 detailing the collection of email addresses should participants wish to enter the prize draw and how this data will be stored. This information is also detailed in the participant information sheet (pg. 3).
How will participants find out about the results/findings of the study? Should think about how this can be done even if participants do not wish to provide their email address.	I have added a section into the participant information sheet advising participants that they can request a summary of the findings by emailing the lead researcher. Please see highlighted text in "what will happen to the results" section on pg. 3 of information sheet.
You say participants will be able to withdraw at any point can you confirm that the JISC online questionnaire system has been set up so that when a participant stops answering questions that none of their answers will be recorded? If this can't be done then must be clear (in participant info screen etc) that if they begin the questionnaire their answers will be recorded and stored (and therefore may be used) even if they stop the questionnaire.	I have changed the information sheet to make it clear that as the data is anonymous, it will not be possible to withdraw data once a participant has completed the study. Please see the highlighted text at the bottom of page one and the "what if I want to withdraw from the study" on pg 3 of the information sheet.
Linked to above if the participants don't give their address and there is no identifiable data provided how will you be able to withdraw someone from the questionnaire if they get in touch with you?	As above, I have changed the information sheet to make it clear that it will not be possible to withdraw(pg.3)

Signature:

Date: 29/01/2021

ER53 CONCLUSION TO ETHICAL REVIEW (if required)

The applicant's response to our request for further clarification or amendments has now satisfied the requirements for ethical practice and the application has favourable opinion from Clinical Psychology Ethics Committee.

Signature:

Position: Lecturer in Applied Psychology/Ethics and Integrity Lead

Date: 8.03.21

ER54 AMENDMENT/S: REQUEST FOR APPROVAL

Subsequent to receipt of ethical approval above, I, the applicant, would like to request the following amendment/s to my original proposal, reference: CLIN830, granted approval on 8th March 2021.

Amendment 1- Widening inclusion criteria from Grandparent Kinship Carers to all types of Kinship Carer over the age of 55 years.

In order to ensure adequate sample size this amendment would mean a wider potential participant pool. A kinship carer is defined as a "relative or family friend who is looking after a child full-time as their parents aren't able to care for them". This means that participants could include aunts and uncles, great aunts and uncles, cousins and family friends and grandparents who are over the age of 55. We feel that widening the sample of potential participants will not alter the quality of the research as we are interested in the unique challenges faced by middle aged and older Kinship Carers. Adding an additional question to the demographic questionnaire will allow us to differentiate between types of carer giving us the option of analysing the data by carer type.

An additional question will be added to the demographic questionnaire asking the participant to state which type of Kinship Carer they are. This question will be multiple choice with the options of Grandparent, Aunt or Uncle, Great Aunt or Uncle, Sibling, Cousin, family friend or other.

All relevant study materials have been amended to reflect the change. These changes are highlighted in yellow on the Study Information/Consent form. On the debrief form the word Grandparent has been removed. No other changes have been made.

Amendment 2- The use of paper copies of the questionnaires

In order to be more inclusive and reach potential participants who do not have the internet or ability to complete the study online we would like to have the option of completing the study through paper.

Paper copies will be given to participants/ organisations when requested. For example, when the researcher is contacting local kinship support groups the option of requesting paper copies of the study will be given.

Paper copies of the study will be identical to the online versions apart from the relevant information regarding storing of the data and the consent form is slightly modified to ensure it is clear that consent has been obtained.

Paper copies will contain a prepaid envelope for participants to be able to return their completed questionnaires.

Completed questionnaires will be stored in a locked filing cabinet until they can be scanned and saved onto the encrypted university drive. Once they have been uploaded onto the university drive and the data inputted into the excel sheet alongside the online data (also stored on the password protected university encrypted drive) they will be destroyed. Once uploaded the data from the paper copies will be kept for the same length of time as the data collected online as detailed in the approved form above.

If the researcher has to transport the completed paper questionnaires at any time (for example if attending a kinship carer support group where people have completed the study) this will be done in a locked file bag and transported straight to the locked filing cabinet.

For the prize draw, the paper copies will give participants the option of leaving either their email or their phone number. This is to include participants who may not have an email address. Participants will be asked to leave one or the other (phone or email) to limit the amount of information stored on an individual. The same data storing principals will apply to this data as in the online study. It will be stored in a separate place to the rest of their data and kept for 1 year before being destroyed.

All relevant study materials have been amended and highlighted in green. Please also see the paper copy consent form which has been amended to allow for completion.

Signature:

Date: 02/07/21

ER55 CONCLUSION TO ETHICAL REVIEW OF AMENDMENT

I can confirm that the above amendment has been reviewed by two independent reviewers. It is their opinion that:

a. Ethical issues have been satisfactorily addressed and no further response from the applicant is necessary,

Signature:

Position: Lecturer in Applied Psychology/Ethics and Integrity Lead

Date: 20.7.21

Acronyms / Terms Used
NHS: National Health Service
SHSS: School of Health in Social Science
IRAS: Integrated Research Applications System
Section: The SHSS is divided into Sections or subject areas, these are; Nursing Studies, Clinical Psychology, C-P

Appendix F- Participant Information Sheet and Consent Form

THE UNIVERSITY of EDINBURGH

Online Participant Information Sheet

Project Title: Exploring the Psychological Health of Middle aged and Older Kinship Carers

Thank you for your interest in taking part in this research study which takes around 20 minutes to complete. Please take time to read the following information carefully and contact us if you have any questions.

What is the purpose of the study?
This study aims to investigate the mental wellbeing of kinship carers over the age of 55 years. A kinship carer is someone who looks after a child full-time or most of the time, usually because the child's parent isn't able to care for them. Previous research has shown that individuals who care for others may have poorer mental wellbeing than those who do not have caring responsibilities. We would like to explore whether this is true for kinship carers over the age of 55, due to the unique factors that come with ageing. We are also interested in factors that might influence mental wellbeing.

We hope that the findings of this study may help to highlight any difficulties faced by middle aged and older kinship carers and help us to develop the most effective supports in the future.

Why have I been invited?
We are looking for kinship carers to take part in this study. To take part you must:

- Be a Kinship Carer who is 55 years or older
- Be currently caring for a child who is not your own, between the age of 0-21 years, who lives with you
- Be fluent in English
- Not have a current unstable mental health condition (e.g. feeling actively suicidal)
- Not have a current cognitive condition (e.g. dementia or brain injury)

Do I have to take part?
No, it is your choice whether or not to take part in the study. If you do decide to take part, you are still free to stop at any time and without giving a reason.

Please be aware that the survey platform collects your responses as you progress through the study. When you press "next" at the end of each section, your responses

will be submitted. It is not possible to withdraw your responses after they have been submitted as your data is anonymous.

What would your participation involve?
We believe it is important to highlight these difficulties and explore the factors that might be contributing. In order to do this, we need collect information from you by asking you to answer a number of questions about yourself.

If you are happy to take part, you will be asked to confirm you give your consent below. Once you have given your consent to take part, you will be asked to fill in a series of questionnaires. These questionnaires will cover a range of topics, starting with demographic information and including questions regarding carer burden, mental health, self-compassion and mindfulness. All the questions in this study are multiple-choice and are completed online. It should take around 20 minutes to answer all of the questions. We believe that kinship carers, and especially those over the age of 55, are a group of people who may suffer more than others in terms of their mental health.

All data collected will be coded, and anonymised, so it will not be possible to identify you from the data you have given.

What are the possible benefits of taking part?
There are no direct benefits but it is hoped that this study will benefit all kinship carers by helping us to better understand and highlight the difficulties faced by this population. It is hoped this research will help to inform future support provided to kinship carers to help alleviate these difficulties. As a thankyou for taking part in this study you can choose to be entered into a prize draw to win one of four £25 amazon vouchers.

What are the possible risks of taking part?
You may find that answering the questions in this study makes you think about your mental health and may highlight difficulties that you are experiencing. For this reason, we have provided the numbers of organisations and helplines that you can contact if you wish to talk about these difficulties or seek support.

What if I want to withdraw from the study?
You are free to stop the study at any point by clicking “withdraw” at the bottom of each section. This will take you to the end of the study where you will find information about where to seek support for you mental health, should you need it, and information regarding how to make a complaint.

What will happen to the results of the research study?
The findings of this study may be reported as thesis results for the lead researcher, discussed at a knowledge exchange event with University of Edinburgh and published in a peer-reviewed journals. You and other people taking part in the research will not be identifiable as a participant on any such scientific publication, public or academic presentation. A summary of the findings will be made available to participants at their

request. If you wish to receive this summary, please contact the lead researcher, Emma Juster (contact details below).

Will my taking part in this study be kept confidential?
Yes and all data collected in this study will be completely anonymous. Your personal data will be processed and stored in accordance with General Data Protection Act (2018). **Your answers to the survey questions will be kept separately to your email address (should you provide it)**. Data will then be uploaded onto the secure and encrypted server used by the University of Edinburgh and will be password protected. Your data will only be viewed by the research team**.**

If you choose to enter the prize draw and leave your email address, this will be stored under password protection on the secure and encrypted University of Edinburgh server for 1 year before being deleted.

With your consent data collected as part of the study will be retained in an anonymised format until August 2022. This is to provide an opportunity for future student researchers to analyse the anonymised data under the supervision of Dr. Azucena Guzman for future ethically approved research. For general information about how we use your data click here.

Who has reviewed the study?
The Clinical Psychology Department, Ethics Review Committee at the School of Health in Social Science at the University of Edinburgh have reviewed the study. The University of Edinburgh is the Sponsor for this study.

Who do I contact for information, advice or complaints if there is a problem?
If you have any questions about the study, please contact the lead researcher, Emma Juster, or Dr Azucena Guzman, Academic Supervisor and Clinical Psychologist,

To discuss the study with someone independent of the research please contact the Deputy Director of Research (Ethics & Integrity) at the University of Edinburgh, Dr Clara Calia,

For any complaints, please contact the Head of School in Health in Social Science, Professor Matthias Schwannauer, stating the study title and nature of the complaint

Consent to take part

- I confirm that I have read and understood the above information.
- I understand that my participation is voluntary and that I can stop the study at any point.
- I understand that it will not be possible to withdraw my data once I have submitted my responses at the end.
- I understand that my anonymous data collected during the study will be used to write a thesis for the Doctorate in Clinical Psychology and may be used to write a peer reviewed article.
- I agree to my anonymised data being stored securely and for it to be used in future ethically approved research
- I understand that if I choose to enter the prize draw for a chance to win an amazon voucher, my email address will be stored securely for 1 year and separate from the answers to my questions
- I agree to take part in the above study.

In case you should require additional support, during or after the study, we recommend the following support services:

1) Samaritans: 08457 909090
2) Breathing Space: (Mon- Thurs 6pm- 2am; Fri 6pm-Mon 6am) 0800 83 85 87
3) Saneline (*national out of hours mental health helpline*): (6pm-11pm) 0300 304 7000
4) Your GP
5) For kinship carers in Scotland the National Kinship Care Advice Service can be contacted for assistance and advice: (Mon- Fri 10am-2.30pm) 0808 800 0006
6) For Kinship Carers in England and Wales, Kinship can be contacted for advice regarding kinship care: (Mon-Fri 9.30am-3.30pm) 0300 123 7015

Thank you for considering taking part!

Appendix G- Demographic Questionnaire

Title Study: Exploring the Psychological Health of Middle Aged and Older Kinship Carers

1. **How old are you?**
2. **How would you describe your gender?** Female, Male, Transgender male, Transgender female, Non-binary, Prefer not to say
3. **Please select your country of residence**- Scotland, England, Wales, Northern Ireland, Other
4. **What is your ethnicity?** White; Mixed or Multiple ethnic group; Asian, Asian Scottish or Asian British; African; Caribbean or Black; Other ethnic group
5. **What is the highest level of education you have completed?** Primary School; Standard grades, GCSEs or equivalent; Scottish Highers, A levels or equivalent; Undergraduate degree; postgraduate degree
6. **What is you total yearly household income (including any benefits you receive)?** Less than £10,000; £10,000 to £19,999; £20,000 to £29,999; £30,000 to £39,999; £40,000 to £49.999; more than £50,000
7. **Are you currently seeking professional help for your mental health?** Yes, No
8. **What relationship are you to the child/ children you are currently a kinship carer for**? Grandparent; Aunt or Uncle; Great Aunt or Uncle; Sibling; Cousin; Other
9. **What sort of Kinship Carer are you**? Informal Kinship Carer (e.g. arrangement made between family members without the involvement of local authority), Formal Kinship Carer (e.g. kinship foster carer, child placed with you under an order granted by the court such as a Special Guardianship Order or by the local authority, or you have adopted your relative)
10. **How many children are you currently a kinship carer for?**
11. **How old are the children you are a Kinship Carer for?**
12. **Do you currently have any other children at home between 0-21 years who you look after?** If so how many? Yes (drop down to choose number); No
13. **How long have you been a kinship carer for?**
14. **What is the reason for becoming a kinship carer?** The child's parent has been deemed unfit to look after them; the child's parent has died; the child's parent is in prison; other reason; prefer not to say
15. **Are you a lone carer (i.e are you the only adult caring for your relative)?** I am the only carer; There is another adult who lives with me who shares caring responsibilities; There is another adult who does not live with me but who shares caring responsibilities
16. **Do you have a job aside from your role as a kinship carer**? Yes, No

Appendix H- Debrief Information

THE UNIVERSITY of EDINBURGH

Online Participant Debrief Sheet

You have now answered all the questions in the study. Thank you very much for taking part.

As a thank you for taking part you can choose to be entered into a prize draw for the chance to win one of four £25 amazon vouchers. Please leave your email below if you wish to be entered into the draw. As stated in the information sheet at the start of this survey, your email address will be stored separately from your answers to the survey questions and deleted after 1 year. If you have been successful in the draw we will use this email address to contact you with your prize.

Email:

The questions you have just answered will help us to explore how being a kinship carer affects psychological health and the factors which may contribute to maintaining good mental wellbeing. If you feel that taking part in this study has highlighted difficulties that you are experiencing then please refer to the organisations and helplines below which you can contact if you wish to seek further support.

We are looking for as many kinship carers as possible to take part in this study. Please help us by sharing the information about this study and the study link with other kinship carers over the age of 55. The study link is: (study link here) should you wish to send this to others.

Thank you again for your time in the completion of this study. If you have chosen to take part in the prize draw, we will be in contact with you via the email you provided should you be chosen as one of our winners.

If there are any other questions regarding the study, to request paper copies of the questionnaires or to request a written summary of the results of the study, please contact the lead researcher using the contact details below.

For further information about the study or if you have any questions please contact:

Lead Researcher:
Emma Juster

Academic Supervisor and Clinical Psychologist:
Dr Azucena Guzman

To discuss the study with someone independent of the research please contact the Deputy Director of Research (Ethics & Integrity) University of Edinburgh
Dr Clara Calia

For any complaints, please contact the Head of School in Health in Social Science
Professor Matthias Schwannauer

Or the College of Arts, Humanities and Social Sciences Research Governance Team at cahss.res.ethics@ed.ac.uk

Data Protection Officer contact information:
Data Protection Officer, Governance and Strategic Planning, University of Edinburgh, Old College, Edinburgh, EH8 9YL. Tel: 0131 651 4114 Email: dpo@ed.ac.uk

In case you should require additional support, during or after the study, we recommend the following support services:

7) **Samaritans** provides confidential non-judgemental emotional support for anyone who is struggling to cope: call free 24hour a day on 116 123 or email jo@samaritans.org
8) **Breathing Space** provides listening, information and advice for people in Scotland feeling low, stressed or anxious: call free on 0800 83 85 87 (Mon-Thurs 6pm- 2am; Fri 6pm-Mon 6am)

9) **Saneline** is a national out-of-hours mental health helpline offering emotional support, guideance and information to anyone affected by mental illness, including family, friends and carers: call free on 0300 304 7000 (4.30pm-10.30pm)

10) Your **GP**

11) For kinship carers in Scotland the **National Kinship Care Advice Service** can be contacted for assistance and advice: 0808 800 0006 (Mon- Fri 10am-2.30pm)

12) For Kinship Carers in England and Wales, **Kinship** can be contacted for advice regarding kinship care: 0300 123 7015 (Mon-Fri 9.30am-3.30pm) or email advice@kinship.org.uk

Thank you!