Understanding the Role of Compassion in the Experience of Caregivers

By:
Poppy Siddell

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Clinical Psychology Unit, Department of Psychology

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Declaration

This thesis is submitted in partial fulfilment of the Doctorate of Clinical Psychology award at the University of Sheffield. It has not been submitted for any other degree or to any other institution.

Structure and Word Counts

Part I: Literature review

Excluding references and tables   6851

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Part II: Empirical Project

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Lay Summary

It is well known that providing care for a loved one puts the caregiver at an increased risk of a range of mental health difficulties. Therefore, supporting caregivers to stay in their role for as long as they wish to, is paramount. One way to do this is through the provision of interventions aimed at reducing distressing feelings such as low mood, stress, and anxiety. Research has shown that alongside the increased risk for negative feelings, caregivers also experience positive aspects of their caregiving role; however, much less is known about these positive factors. For example, it is not yet known whether interventions aimed at increasing these positive aspects, rather than decreasing negative symptoms, are effective for this population. In order to better understand how to support caregivers, a more holistic consideration of their experiences is required. A group of therapies, named 'third wave' therapies are thought to focus these positive aspects of the human experience such as acceptance, mindfulness, self-compassion, values, and relationships.

Part I includes a literature review to examine the effectiveness of third wave interventions in increasing positive outcomes for caregivers. Findings showed that third wave interventions are moderately effective in increasing positive outcomes regardless of caregiver population, type of intervention or type of outcome. When combined with existing research suggesting that third wave interventions are effective in reducing negative symptoms, these results indicate that such interventions may provide a more holistic alternative to other types of therapy for caregivers.

Although effective interventions exist to support caregivers, in general, the utilisation of support by this population is low. Consequently, Part II used both closed and open-ended questions to explore the role of compassion in caregivers of people with dementia who are making decisions whether to access support. This is because previous research suggests that

the ability to identify ones needs and act accordingly is related to compassion. There is currently very little known about the role of compassion in this population.

When broken down, compassion is thought to have three main 'flows', self-self, other-self and self-other. This study was particularly interested in the flows of self-self and other-self and as such, both questionnaires and open-ended questions were used to explore these concepts in relation to the level of support use of 52 caregivers who participated in the study. The results of this study were mixed: the closed-ended questions found that factors such as self-self, other-self compassion did not predict level of support use (defined as low, medium, high); however, findings from the open-ended questions suggested that caregiver's perceptions of other-self compassion did impact whether they chose to accept the support offered to them.

When combined, these findings suggest that the consideration of positive aspects of caregiving, such as compassion, is valuable both when considering the type of support to offer caregivers and when considering the accessibility and acceptability of the support being offered. As this is an emerging area of research, future studies further exploring the role of compassion in caregiver populations is recommended.

Acknowledgements

Table of Contents

Part I: Literature Review

The effectiveness of third wave interventions in improving positive psychology outcomes in family caregivers: A Meta-analysis

Part II: Empirical Project

Compassion and the use of support by family caregivers of people with dementia: An

exploratory mixed-methods study

Part I: Literature review

The effectiveness of third wave interventions in improving positive psychology

outcomes in family caregivers: A Meta-analysis

Abstract

Objectives

Caring for an individual with chronic health conditions puts the caregiver at an increased risk of a range of mental health difficulties. To provide adequate support for caregivers, it is important to identify effective interventions. There is evidence to suggest that there is a conceptual difference between the positive and negative aspects of caregiving. However, there is a dearth of literature exploring the effectiveness of interventions in increasing positive outcomes. The purpose of this meta-analysis was to examine whether third wave therapies are effective in improving positive outcomes for family caregivers.

Methods

A systematic search was performed using PsycINFO, MEDLINE, CINAHL and Scopus. Key search terms related to: third wave therapies and caregivers. An assessment of methodological quality was completed. A random effects meta-analysis was utilised to examine the effectiveness of third wave therapies in increasing positive outcomes.

Results

A total of twenty-five studies were included in the meta-analysis ($n = 1139$). Moderate heterogeneity was observed, and this remained following moderator analyses. A positive small-sized overall effect was found ($d = .321$; 95% CI [.130-.513]), supporting the hypothesis that third wave therapies are effective for increasing positive outcomes in caregivers.

Conclusions

This meta-analysis provides evidence that third wave interventions have a moderately sized positive effect on positive outcomes for caregivers. These findings, combined with research suggesting that third wave interventions are effective in reducing negative symptoms in this population, suggests that third wave interventions are a robust alternative to more traditional therapies in caregiver populations.

Practitioner Points

- Third-wave therapies should be considered as an effective intervention for caregivers.

- The type of intervention was not found to significantly moderate the effectiveness of the intervention, indicating that there might be underlying process that may be a focus of future research.

- There is a lack of data on the effectiveness of compassion-focussed intervention in this population; Future research exploring the role of compassion would be beneficial to increase understanding of potential targets for intervention.

Key words: 'caregivers', 'interventions', 'third-wave', 'psychotherapy', 'positive outcomes', 'mindfulness', 'compassion', 'acceptance'

Introduction

It is estimated that as many as 8.8 million adults may be providing care to a relative, friend or loved one, and this number appears to be increasing (Carers UK, 2019). It is well documented that caring for an individual with chronic health conditions puts the caregiver at an increased risk of a range of mental health difficulties (Ho et al., 2009) such as anxiety (del-Pino-Casado, 2021) and depression (Cooper et al., 2007). Consequently, there is a need for an increased understanding of how to support the wellbeing of caregivers, which is reflected in the commitment to carers made in the National Health Service (NHS) Long Term Plan (NHS, 2019). In order to provide services that support the emotional needs of caregivers, it is important to identify effective interventions that are acceptable to the population.

Psychotherapeutic interventions, particularly Cognitive Behavioural Therapy (CBT), have consistently been found to be somewhat effective in reducing a variety of symptoms in a range of caregiver populations (e.g. Kwon et al., 2017; Hopkinson et al., 2019; Panzeri, Ferrario & Vidotto, 2019) with the strongest evidence being for reduction in symptoms of depression (Gallagher-Thompson & Coon, 2007). The majority of the literature examining the effectiveness of therapies for caregiver populations is focussed on the ability of the interventions to reduce distressing symptomatology such as stress, anxiety, and depression, as well as the experience of caregiver burden. However, as is the case in many areas of clinical psychology, this focus on 'negative' functioning fails to consider the impact of 'positive' aspects of functioning, and there is a growing movement towards the consideration of both factors when examining the effectiveness of interventions (Joseph & Wood, 2010). This is particularly pertinent, as there is evidence to suggest that the positive and negative aspects of caregiving are conceptually separate, rather than being opposite ends of a continuum (Rapp & Chao, 2000). Therefore, the over-representation of interventions focussed on relieving the

negative aspects of the caregiving experience may mean that positive areas of their experience are neglected.

Positive aspects of caring

There is an emerging evidence-base examining the impact of positive experiences of caregiving on caregiver wellbeing (e.g. Mackenzie & Greenwood, 2012; Quinn & Toms, 2019; Hong & Harrington, 2016). Positive feelings of caring have been found to be significantly related to caregiver depression, perceptions of burden and physical health, with those reporting high levels of positive feelings in their caregiving role being less likely to report feelings of depression, burden, and poor health themselves (Cohen, Colantonio & Vernich, 2002). Factors such as self-compassion, mindfulness and self-esteem have also been found to protect against the development of depression in caregivers of people with cancer (Nijboer et al., 1999; Hsieh et al., 2019). Similarly, the extent to which caregivers are able to find meaning and gratification as part of their caregiving role is associated with higher levels of resilience and perceived ability to cope (Hirschfield, 1983). In light of these findings, it may be apposite to not only consider whether interventions can reduce negative symptomatology but also whether they can increase positive experiences for caregivers, as there have been calls for future research to address this gap in the literature (Hsieh et al., 2019).

Third wave interventions for caregivers

Since Hayes' seminal paper in 2004, there has been a growing evidence base on the effectiveness of so called "third wave" approaches for a variety of mental health conditions (Ost, 2008). These third wave approaches were delineated from traditional Cognitive Behavioural Therapy (CBT) due to their broader focus on experiential and indirect change processes, rather than the more specific behaviour change or symptom-based foci of CBT

(Hoffman, Sawyer & Fang, 2010). Third wave approaches are therefore thought to emphasise alternative aspects of the human experience such as acceptance, mindfulness, self-compassion, values, and relationships (Hayes, 2004), with the relief of any negative symptomatology being a side-effect rather than a focus.

The popularity of applying these therapies in caregiver populations is increasing. The specific therapies being applied to this population include: Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999), Dialectical Behaviour Therapy (DBT; Linehan, 1993), Mindfulness-Based Cognitive Therapy (MBCT; Segal, Williams, & Teasdale, 2018), Compassion-Focused Therapy (CFT; Gilbert, 2009), Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 1982). Although there is a discrepancy in the literature about whether MBSR is included as a third wave therapy (Feliu-Soler et al., 2018), as the function and process of MBSR is conceptually similar to that of MBCT and other mindfulness-based approaches, it is often included in any reviews of third wave therapies (e.g. Feliu-Soler et al., 2018).

Mindfulness-based Interventions

MBSR. Emerging from Buddhist principles, MBSR was originally developed by Jon Kabat-Zinn (1982) and comprises of a series of mindfulness practices integrating breath work, shifting the focus of attention, Yoga and meditation. It is usually delivered in a group over eight, weekly, two-hour sessions and a four-hour silent retreat (Kabat-Zinn, 1982). MBSR has been used successfully with people with a wide range of health conditions (e.g. Grossman et al., 2004) and, as a result, interest in its applicability to caregiver populations is increasing (Jani et al., 2018). Adaptations for caregivers have been suggested, with caregivers of stroke survivors expressing reservations about the time commitment required to complete the intervention (Jani et al., 2018).

MBCT. MBCT was directly developed from traditional CBT with the original aim of improving longevity of recovery for people who had received treatment for depression (Segal, Williams & Teasdale, 2002). MBCT represents an integration of both cognitive and mindfulness-based techniques to increase connection to the present, reduce rumination (Hoffman, Sawyer & Fang, 2010) and is closely linked with MBSR (Wood, Gonzalez & Bardon, 2015). The applicability of MBCT for caregivers had been supported, partly due to its focus on changing the client's relationship with their thoughts, rather than changing thoughts directly, and partly due to its manualised nature, which allows for treatment to be brief and structured (Wood, Gonzalez & Bardon, 2015). Treatment with MBCT is often completed in a group setting and consists of eight sessions (Coelho, Canter, & Ernst, 2013). Specific modifications and recommendations for adapting MBCT for caregivers of people with cancer have been suggested (Wood, Gonzalez & Bardon, 2015) such as the consideration of burden experienced as part of the caregiver role and a focus on specific emotions commonly experienced by caregivers (e.g. anger, sadness, guilt; Kim, 2005).

Emerging evidence suggests that mindfulness-based interventions (including MBCT and MBSR) have been shown to be effective in reducing experiences of depression, anxiety, stress, and subjective burden in a range of caregiver populations (e.g. Dementia: Shim et al., 2020; Palliative care: Jaffray et al., 2015; Cancer: Daken & Ahmad, 2018).

ACT

ACT was first developed using theoretical underpinnings from relational frame theory (Hayes, Strosahl, & Wilson, 1999) to provide a structure for understanding the contextual relationship between cognition and language. It is centred around the concepts of psychological flexibility, acceptance and experiential avoidance (Flaxman & Bond, 2006). ACT is typically completed over twelve to sixteen weekly sessions usually in an individual

context, but it has also been delivered in group contexts depending on the needs of the population (Petkus & Wetherell, 2013). There is evidence to suggest that caregivers who experience a high level of experiential avoidance, which is defined as the preference for controlling or avoiding distressing thoughts, feelings or sensations (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996), also experience higher levels of distress (Spira et al., 2007). Consequently, the applicability of ACT as an intervention for caregivers has been supported and there is an emerging evidence base suggesting that ACT is effective in reducing experiential avoidance (Losada & Marguez-Gonzalez, 2015). Proposed adaptations for caregiver populations include preparatory work prior to the intervention and providing interventions at convenient locations (Lloyd, 2016).

DBT

DBT represents an extension of CBT that integrates CBT, mindfulness and a dialectical perspective to improve an individual's ability to regulate their affect (Linehan, Amstrong, & Suarez, 1991). It was originally developed for use with people with borderline personality disorder with the aim of reducing episodes of self-harm (Linehan, Amstrong, & Suarez, 1991). However, it has now been utilised and been shown to be effective with a range of presentations (Burmeister et al., 2014). Traditional DBT is delivered in a group format with additional individual sessions and consists of weekly skills-based sessions over the course of a year. A condensed version of this intervention has also been developed for use with caregivers of older adults who are at risk of abuse (Drossel, Fisher & Mercer, 2011).

CFT

CFT is an integrative approach that combines neurobiology, CBT, evolutionary psychology and mindfulness (Gilbert, 2009). Its primary aim is reducing shame and self-criticism by increasing self-compassion and has therefore been recommended as an

intervention for individuals experiencing high levels of shame or self-criticism (Gilbert, 2009). CFT can be delivered in individual or group contexts, and as it is not considered to be a manualised approach, the length of the intervention can vary. Interventions focussing on compassion have been shown to be acceptable and effective for caregivers of people with dementia (Danucalov et al., 2017; Collins, Gilligan & Poz, 2018).

Use of the term "third wave therapies"

It is acknowledged that the use of the term 'third wave' to describe this group of interventions is controversial (Dimidjian et. al., 2016). Proponents of this view have argued that, rather than representing a 'new wave' of CBT, third wave interventions are instead more of an extension of traditional CBT (e.g. Hofmann & Asmundson, 2008). Indeed, several of the creators of therapies typically classified as third wave have distanced themselves from the term, instead viewing their therapies as stemming from traditional CBT principles rather than being new developments (Hoffman, Sawyer & Fang, 2010). Regardless, the 'term third' wave is still routinely used in the evidence base and in clinical practice as an umbrella term for this group of therapies and as such, in line with other research in the area, this review will continue to refer to them using this terminology (e.g. Ost, 2007; Feliu-Soler et al., 2018).

Aims

The current meta-analysis aimed to examine whether third wave therapies (i.e. MBI, ACT, CFT, DBT, or population specific combinations thereof) are effective in improving positive outcomes for family caregivers. Positive outcomes are defined as outcomes capturing areas of positive functioning (Joseph & Wood, 2010). Moderators which might impact the magnitude of the effects of the interventions (i.e. age, gender, diagnosis of the individual receiving care, outcome type and intervention type) were also analysed.

Method

A systematic search of the literature using comprehensive search terms was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement (PRISMA; Moher et al. 2009). The review protocol was pre-registered on PROSPERO at

https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020170283

Search Strategy

Electronic searches were conducted using the pre-defined search criteria. Searches were conducted on the PsycINFO, MEDLINE, CINAHL and Scopus databases. A search for unpublished literature was also conducted using OpenGrey (http://www.opengrey.eu/search/) and the first 10 pages of Google Scholar. The reference lists of included articles were hand searched to identify any relevant articles that may have been missed by the initial search. Search terms were combined using the Boolean operators (AND / OR) and truncation or wildcards (e.g. *). Key search terms included were those relating to: (a) third wave therapies AND (b) caregivers (Table 1). Only studies published in the English were included. The search was completed December 2020 and any studies published up to and prior to this date were considered.

Table 1

Search terms used in the systematic search

Caregivers	Third wave therapies
"caregiver" OR "carer" OR "caring" OR "caregiving" OR "family caregiver" OR "family carer" OR "informal caregivers" OR "informal carer" OR adult OR "old* adult*" OR "age*" OR "old* person*" OR "old* people" OR "old* patient*" OR "elder*" OR "geriatric*" OR "senior*"	"Mindfulness" OR "mindfulness-based" OR "meditation" OR "mindfulness based" OR "MBSR" OR "MBCT" OR "acceptance" OR "acceptance-based" OR "acceptance based" OR "acceptance and commitment therapy" OR "ACT" OR "DBT" OR "dialectical behaviour therapy" OR "compassion" OR

	"compassionate" OR "compassionate mind" OR "compassion-focussed" OR "CFT"

Note. *indicates that the specified term may form part of another word

Inclusion/exclusion criteria

The full inclusion and exclusion criteria are described in Table 2 using the PICO domains. Any study examining the effectiveness of third wave interventions for adult family caregivers of adults with chronic health conditions in improving positive psychology outcomes were included. Family caregivers were defined as anyone who self-identifies as a caregiver of a family member, spouse, friend or loved one who does not do so in a professional capacity.

Studies including mixed data from participants across the lifespan were included if data from individuals who are providing care for persons over ≥18 years of age could be disaggregated from those caring for persons <18 years of age. Interventions may have been conducted as 1:1 or group sessions and interventions will not be excluded on the basis of their length or frequency. For the purposes of this review, the following interventions were categorised as representing 'third wave' therapies: ACT, DBT, MBSR, MBCT, CFT. Study specific interventions integrating a mixture of these therapies were also included, to account for their adaptation to the specific needs of the caregiver populations.

Positive outcomes were characterised as falling under the five domains of positive functioning as defined by Rusk and Waters (2013) and were supplemented using outcomes commonly used to measure the effectiveness of the specified interventions. These included: Mindfulness, gratitude, acceptance, self-compassion, psychological flexibility, life satisfaction, positive affect (e.g. happiness), self-efficacy, self-esteem, resilience, spirituality, pleasurable events.

Table 2

Inclusion and Exclusion criteria

	Review questions *What is the effectiveness of third wave interventions in improving positive psychology outcomes in family caregivers?*	
	Inclusion criteria	**Exclusion criteria**
Population	Adult family caregivers (i.e. those providing care in a non-professional capacity who are >18 years old) of adults (>18 years old) with chronic health conditions (e.g. cancer, diabetes, dementia)	Formal caregivers who are providing care for the person in a professional capacity. Family caregivers who are <18 years old. Family caregivers who are providing care for someone who is < 18 years old. Family caregivers who are providing care for an adult who does not have a chronic health condition (e.g. neurodevelopmental disorders).
Intervention	'Third wave' interventions to be included are as follows: Acceptance and commitment therapy (ACT), Dialectical behavioural therapy (DBT), Mindfulness-based interventions (MBI), Compassion-focused therapy (CFT)	Interventions from therapeutic modalities other than third wave (psychodynamic, CBT).
Comparator	The comparators are expected to be treatment as usual, waiting list control or no treatment control. Studies detailing positive psychology outcomes following third wave approaches, without a named comparator, will also be included.	N/A
Outcomes	Positive psychology outcomes are measured as an outcome/s of the intervention. Positive psychology outcomes to be included are as follows: Mindfulness, gratitude, self-compassion, psychological flexibility, life satisfaction, positive affect (e.g. happiness), self-efficacy, self-care, resilience, spirituality, pleasurable events.	Studies measuring outcomes other than those specified.

Data extraction

Storage, management and de-duplication of electronic searches was be completed using Mendeley. The main researcher screened titles and abstracts of the retrieved studies using the defined search criteria. A full text review of studies meeting the search criteria was then completed to ascertain eligibility for inclusion. Of these, 20 percent were also screened by a second researcher and any disagreements were discussed by the authors until a consensus was reached. A total of 95% agreement was achieved.

Data extraction was completed by the lead researcher using a predefined extraction form developed from the data extraction templates available from the Cochrane handbook (Appendix A). Extracted data includes: Methods (study design, method of allocating to groups), participant demographics (number, age, sex, country, condition of the person receiving care, relationship to person receiving care), intervention (type of intervention, format of delivery), measures used for outcomes standardised measures relating to positive psychological outcomes), effect. A proportion of the extracted data was checked by a peer to ensure any relevant information was correct and present. Level of agreement was assessed by calculating the percentage of agreement between the two raters, with a high level of agreement being achieved (90%). As before, any disagreements were discussed until a consensus is reached.

Quality Assessment

The quality of the included studies was assessed using a modified version of the Downs and Black Checklist (1998; Appendix B) which was chosen due to its applicability for use when assessing the quality of both randomised and non-randomised trials of interventions (Higgins & Green, 2011). The Checklist is comprised of 27 items that assess aspects of study quality such as the quality of reporting, external validity, risk of bias, confounding and

whether or not the study has adequate power. Each item was rated as either 1= yes or 0= no/unclear, apart from item 5 which was rated as 2= yes, 1= partially and 0= no. Therefore, the maximum score was 28. The item assessing the adequacy of the study's power was modified to account for the fact that a large number of the included studies were pilot or feasibility trials. Consequently, such studies were given a full score of 2 if they reported the power calculation in the design of their study and achieved adequate power for a pilot/feasibility study, even if they failed to achieve full statistical power for the overall study. In the present study, quality assessment was performed only to examine the quality of included studies and not to exclude any studies nor modify the weight of the studies included for meta-analysis.

The meaningfulness of summed scores of study quality has been contested (Herbison, Hay-Smith & Gillespie, 2006). Therefore, rather than using the summed score to assess quality, the present review opted to use qualitative labels as opposed to presenting the summed score. In line with other reviews utilising the Downs and Black Checklist, the following categories were applied to ease the interpretation of the quality assessment and permit comparison: >20= very good, 15-19= good, 10-14= fair, <10 poor (e.g. Silva et al., 2016). Similarly, a traffic light system was used to capture the study quality for each item with 1/yes= green, 0/unclear/partial= amber and 0/no= red. The lead reviewer assessed the quality of the included studies. A selection of the included papers was also assessed for quality by a peer researcher to increase the validity of ratings. Any disagreements in the quality ratings were discussed until a consensus was reached. Level of agreement was assessed by calculating the percentage of agreement between the two raters.

Data analysis

To examine the effectiveness of third wave therapies on positive outcomes, the outcomes of each study was systematically combined using a random effects meta-analysis which was conducted using the Comprehensive meta-analysis (CMA) software. A random effects model was deemed appropriate due to the diversity of studies and caregiver populations, which was anticipated to result in considerable heterogeneity. Similarly, due to the expected levels of heterogeneity, all studies were included and no outliers were automatically excluded from the analysis.

For each study, pre-post intervention means and standard deviations were used to calculate the effect size using a common metric to permit comparison, which in this case was Cohen's *d*. For studies that did not report pre-post effect size or confidence intervals, the author calculated these using the available data, providing there was sufficient data to do so. In studies reporting multiple outcomes, outcomes were combined to produce a single synthetic variable which was computed using the mean of the effect sizes and variance (Card, 2015). This approach was adopted as there was assumed to be high levels of correlation between variables, however, it is acknowledged that results should be interpreted with caution as this method may have resulted in an over-estimation of variance.

Heterogeneity. Heterogeneity was examined using the Q and I^2 test statistics with the variance as indicated by the I^2 statistic being considered to be low (25%), moderate (50%) or high (>75%; Viechtbauer, 2010). Forest plots indicating effect sizes and confidence intervals were also produced. If these analyses yielded significant results, moderator analyses were conducted as a means of examining the source of the variance.

Three potential moderators were identified *a* priori based on the characteristics of the included studies and existing evidence base. These were intervention type, outcome type and the diagnosis of the individual receiving care. As such, subgroup analyses were conducted for

these potential moderators providing there were groups with at least three contributing papers (Card, 2015), using the difference between the Cohen's *d* in each subgroup. Groups with less than three papers were either combined based on similarity to other groups (e.g., outcome type), or added into a 'mixed' group (e.g., interventions). The moderating effects of continuous variables such as gender (%female) and age were examined using meta-regression.

Publication bias. The concept of publication bias relates to the over-publication of studies with significant results. Therefore, any review that considers published data has the potential to result in an over-estimation of study effects as a consequence of this bias (Ahmed, Sutton & Riley, 2012). Although the present review aimed to reduce this by including the grey literature (Borenstein et al., 2021), there is still a potential of publication bias to influence the results. As such, it is important to examine the publication bias of the included studies. Several methods for examining the level of publication bias in the present meta-analysis were employed as a multi-pronged approach is often recommended (Card, 2015).

Firstly, a funnel plot was generated using CMA. A Funnel plot is a graph comparing the study effect size to its sample size. When using funnel plots, if the observed studies are observed to be evenly distributed around the pooled effect size, the absence of publication bias can be assumed. Next, the trim-and-fill method (Duval & Tweedie, 2000) was employed to examine any asymmetry in the funnel plot and to adjust for missing studies (Shi & Lin, 2019). Following this, Egger's regression test (Sterne & Egger, 2005) was used to regress the standardised effect measure with a measure of precision (Peters et al., 2006) with a significant *p* value being indicative of the presence of asymmetry in the funnel plot which in turn, suggests the presence of publication bias. Lastly, the fail-safe *N* (Rosenthal, 1979) was used to provide a calculation of the number of studies with non-significant results that would

be required to render the *p* value of the meta-analysis non-significant ($p = >.05$. This is deemed to be insufficient if the fail-safe N falls below $5k + 10$ ($k =$ the number of included studies; Rosenthal, 1979). In this case, the fail-safe N would have to fall below 125 for it to be deemed insufficient.

Results

Study Characteristics

The process of study selection and inclusion can be seen in Figure 1. Following de-duplication, a total of 4,984 studies were retrieved by the searches. Following an initial sift of the titles and abstracts of the retrieved studies, a total of 136 studies were identified for full-text review. Of these, a total of 30 studies were deemed to be eligible for inclusion, however, five studies lacked sufficient data to permit calculation of the effect size and confidence intervals and were therefore excluded, leaving 25 studies to be included in the meta-analysis. Eleven (44%) of the included studies were randomised controlled trials (RCT). The characteristics of the included studies can be found in Table 3.

Figure 1

PRISMA Diagram
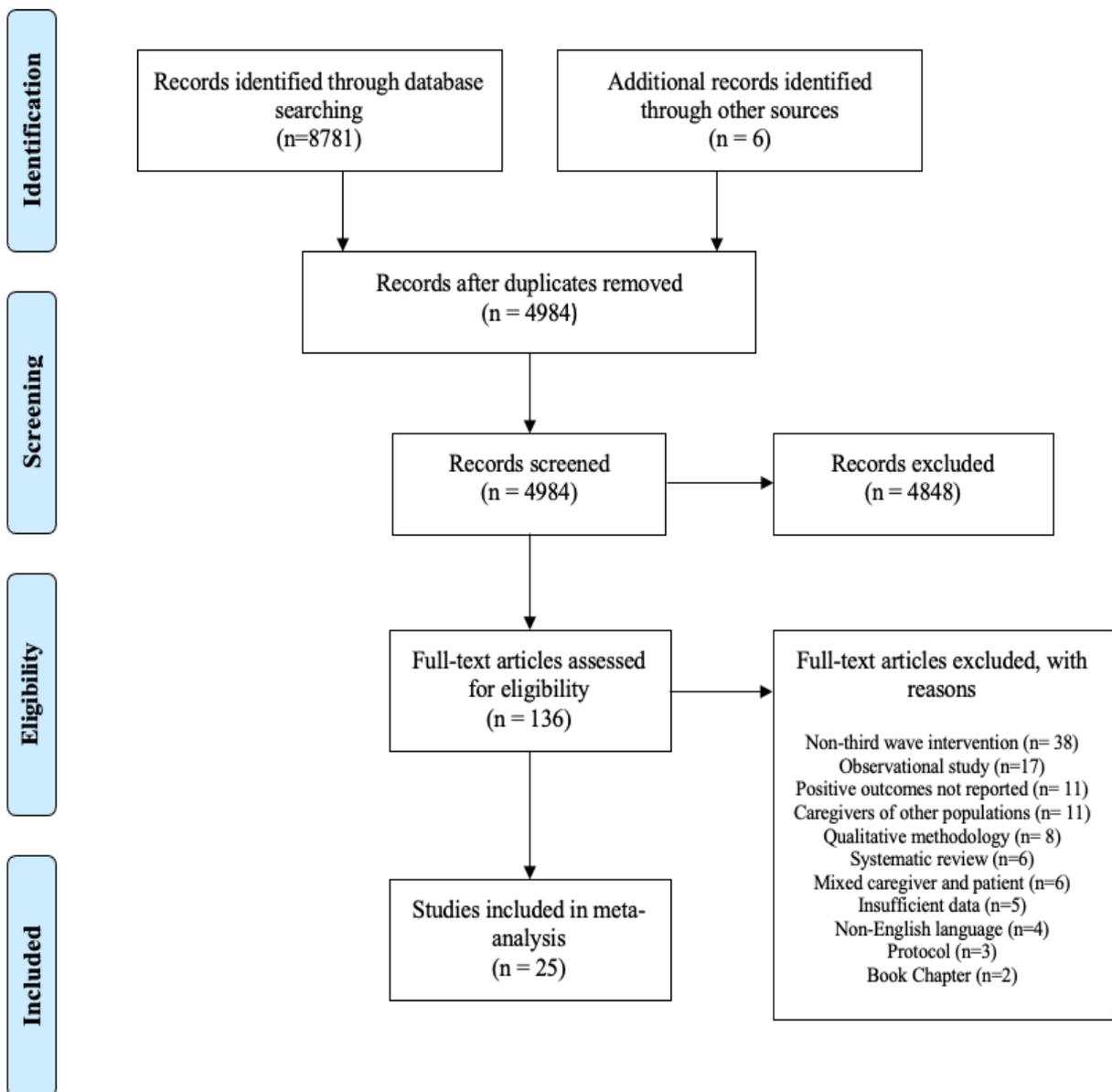
Table 3

Study Characteristics

Study no.	Author	Design	Country	Participants						Intervention/s
				N of caregivers	Mean/median age (SD/range)	Sex (%female)	Condition/s	Relationship to care recipient		
1.	Bannon et al. (2020)	RCT	US	17	48.88 (10.62)	75%	Stroke	10 spouses; 4 child; 1 parent; 1 sibling		'Recovering Together': Study specific (CBT, DBT, trauma informed hybrid)
2.	Berk et al. (2019)	Single-arm feasibility study	Netherlands	14	70.75 (8.14)	71%	Dementia	Partners		TANDEM: Study specific (MBSR and MBCT hybrid)
3.	Brinie et al. (2010)	Single arm, non-randomised study	Canada	21	62.8 (-)	52%	Mixed cancer	20 spouses; 1 unmarried partner		Modified MBSR
4.	Cheung et al. (2020)	RCT	China	57	56 (-)	81%	Dementia	4% spouse, 39% child, 3% grandchild, 5% child-in-law, 3% 'other'		Modified MBSR and MBCT
5.	Drossell, Fisher & Mercer (2011)	Single arm, non-randomised study	US	24	-, (38- 87)	79%	Dementia	6 spouse, 14 child, 3 'other'		DBT
6.	Hearn, Cotter & Finlay (2019)	Randomised-controlled feasibility study	UK	55	44.0 (11.1)	47%	Spinal cord injury	-		'Breathworks': Study specific mindfulness intervention

7.	Ho et al. (2016)	Single arm, non-randomised study	US	20	60.9 (10.9)	95%	Dementia	13 child, 1 grandchild, 4 spouse, 2 friends	Modified MBSR
8.	Hoppes et al. (2012)	Single arm, non-randomised study	US	11	63.8 (44 to 81)	91%	-	4 child, 7 spouses	Modified MBSR
9.	Hou et al. (2014)	RCT	China	141	57.49 (8.83)	83%	-	26 Spouse, 30 child, 12 parents, 2 other relatives	Modified MBSR
10.	Köhle et al. (2021)	RCT	Netherlands	203	55.89 (10.72)	71%	Mixed cancer	Partners	'Hold on, for each other': Study specific (ACT, mindfulness and self compassion)
11.	Kor, Liu & Chien (2019)	Pilot RCT	China	36	57.1 (S.D. = 10.6)	83.3%	Dementia	25 children, 6 spouses, 3 children-in law, 2 siblings	Modified MBCT
12.	Lloyd (2016)	Pilot RCT	UK	18	-	89%	ABI	7 parents, 4 sibling, 3 wives, 2 'other relatives', 2 children	ACT
13.	Losada et al. (2015)	RCT	Spain	135	-	84%	Dementia	68 children, 55 spouse, 12 'other'	ACT

14.	Mallya & Fiocco (2019)	Non-randomised pre-post controlled study	Canada	33	64.18 (6.69)	85%	Any age-related neurodegenerative disease	11 Parent, 20 spouse, 2 other	MBSR
15.	Mosher et al. (2019)	Pilot RCT	US	50	61.64 (11.52)	88%	Advanced lung cancer	19 spouses, 6 'other'	ACT
16.	Oken et al. (2010)	Pilot RCT	US	31	62.50 (11.61)	81%	Dementia	23 spouses, 8 children	Adapted MBCT
17.	Paller (2015)	Single arm, non-randomised study	US	20	62.5 (-)	80%	Cognitive decline, Dementia	13 spouses, 5 children, 1 Daughter-in-law, 1 Mother-in-law	Study specific (MBSR with ACT and DBT)
18.	Schellekens et al. (2017)	RCT	Netherlands	44	60.8 (8.2)	57%	Lung cancer	Spouses	Modified MBSR
19.	Stonnington et al. (2016)	Single arm, non-randomised study	US	18	60.3 (8.6)	78%	Transplant patients	-	Mindfulness based resilience training: Study specific (MBSR, ACT and SMART) stress management and resilience training
20.	Theiling (2016)	RCT	Netherlands	139	55.4 (10.68)	71.9%	Mixed cancer	Partners	'Hold on, for each other': Study specific (ACT, mindfulness and self-compassion)
21.	Ugalde (2018)	Single arm, non-randomised study	Australia	13	57 (-)	46%	Motor Neuron Disease	12 spouse, 1 child	Study specific: self-care, problem-solving and mindfulness

22.	Van den Hurk et al. (2017)	Mixed-methods pilot study	Netherlands	16	60.9 (30–76)	56%	Lung cancer	-	Modified MBSR
23.	Vranceanu et al. (2020)	RCT	US	58	-	67%	Neuro ICU	46 Spouses, 7 parents, 2 siblings, 3 'other'	'recovering together': Study specific (CBT, mindfulness, positive psychology)
24.	Whitebird et al. (2013)	RCT	US	78	56.8 (9.9)	88.5%	Memory loss consistent with dementia	-	MBSR
25.	Zarei (2018)	RCT	US	26	60 (13)	88%	Dementia	18 children, 8 spouse/partner	MBCT

Note. RCT: Randomised Controlled Trial; US: United States; UK: United Kingdom; -: Not reported; ABI: Acquired Brain injury; ICU: Intensive Care Unit;

CBT: Cognitive Behavioural Therapy; DBT: Dialectical Behaviour Therapy; MBSR: Mindfulness-based Stress reduction; MBCT: Mindfulness Based

Cognitive Therapy; ACT: Acceptance and Commitment Therapy.

Sample

From the 25 studies, data representing 1,139 participants were extracted. Of these, the vast majority were female and the mean age was 60 years old. Two studies represented data from the same group of participants (Thieling, 2016; Köhle et. al., 2021) and therefore only data pertaining to the sample in the larger study (Köhle et. al., 2021) was included. A range of caregiver groups were also included, with the main diagnoses of the individual's receiving care being dementia (*n*= 11; 44%) and cancers (*n* = 6; 24%). Of the studies reporting the relationship of the caregiver to the care recipient, 47% were partners, 12% were adult children, 4% were parents, 3% were 'other' and 1% were siblings. The remaining 33% consisted of friends, adult children-in-law and those who declined to answer. Just under half of the included studies were conducted in the United States (*n* = 11; 44%).

Interventions

Table 4 summarises the interventions and control groups utilised in the included studies. The most common interventions utilised in the included studies were study specific interventions integrating multiple third wave therapies (*n* = 10; 40%), modified versions of MBSR (*n*= 9; 36%), MBCT (*n*= 4; 16%) and ACT (*n* =3; 12%). The majority of interventions were delivered in a group context (*n*= 15; 60%) or to patient-caregiver dyads (*n*= 4; 16%).

Outcome Criteria

Table 5 summarises the main measures used to capture positive outcomes in the included studies. Of the 25 included studies, a total of 56 positive outcomes were measured. The most commonly captured outcomes in these studies were mindfulness (*n*=15; 60%) and self-compassion (*n*= 6; 24%). Although only the pre- and post-intervention outcomes were

used in this meta-analysis, 64% of studies also reported the effects of the interventions at follow-up, with the length of time ranging from two weeks to six months.

Table 4.

Summary of intervention and control groups

Author	Intervention/s		Control	
	Type	Mode of delivery	Type	Mode of delivery
Bannon et. al. (2020)	'Recovering Together': Study specific (CBT, DBT, trauma informed hybrid)	Patient-carer dyads	Minimally enhanced usual care	Three-page informational pamphlet
Berk et. al. (2019)	TANDEM: Study specific (MBSR and MBCT hybrid)	Patient-carer dyads		
Brinie et. al. (2010)	Modified MBSR	Group (+Patient-carer dyads)		
Cheung et. al., (2020)	Modified MBCT	Group	MBSR	Group
Drossell, Fisher & Mercer (2011)	DBT	Group		
Hearn, Cotter & Finlay (2019)	'Breathworks': Study specific mindfulness intervention	Self-directed web-course	Psycho-education	Weekly e-mail for 8 weeks, providing psychoeducational materials on SCI
Ho et. al. (2016)	Modified MBSR	Group		
Hoppes et. al. (2012)	Modified MBSR	Group		
Hou et. al. (2014)	Modified MBSR	Group	Self-help	A self-help booklet with eight chapters of supportive information and health education
Köhle et.al. (2021)	'Hold on, for each other': Study specific (ACT, mindfulness and self-compassion)	Web-based	Waiting list control	

	Personal feedback vs. automated feedback			
Kor, Liu & Chien (2019)	Modified MBCT	Group	Usual family care and brief psycho-education program	Seven session brief psycho-education program
Lloyd (2016)	ACT	Group	Enhanced treatment as usual	Two session ACT based group with progressive muscle relaxation
Losada et.al. (2015)	ACT	1:1 sessions	Treatment as usual	
Mallya & Fiocco (2019)	MBSR	Group		
Mosher et. al. (2019)	ACT	Patient-carer dyads (+some 1:1 sessions)	Education and support	Supportive listening and signposting
Oken et. al. (2010)	Adapted MBCT	1:1 sessions	Psychoeducation	6-week psychoeducation group
Paller (2015)	Study specific (MBSR with ACT and DBT)	Group		
Schellekens et. al. (2017)	Modified MBSR	Group	Treatment as usual	
Stonnington et. al. (2016)	Mindfulness based resilience training: Study specific (MBSR, ACT and SMART) stress management and resilience training	Group		
Theiling (2016)	'Hold on, for each other': Study specific (ACT, mindfulness and self-compassion) Personal feedback vs. automated feedback	Web-based	Waiting list control	
Ugalde (2018)	Study specific: self-care, problem-solving and mindfulness	Group		
Van den Hurk et. al. (2017)	Modified MBSR	Group		
Vranceanu et. al. (2020)	'recovering together': Study specific (CBT, mindfulness, positive psychology)	Patient-carer dyads	Health education control	Dyads

| Whitebird et. al. (2013) | MBSR | Group | Community caregiver education and support | Group |
| Zarei, S. (2018) | MBCT | Telehealth: sessions took place over zoom | Treatment as usual | |

Note. CBT: Cognitive Behavioural Therapy; DBT: Dialectical Behaviour Therapy; MBSR: Mindfulness-based Stress reduction; MBCT: Mindfulness Based

Cognitive Therapy; ACT: Acceptance and Commitment Therapy; SCI: Spinal Cord Injury.

Table 5.

Summary of outcomes used

Author	Outcome/s	Measures used
Bannon et al. (2020)	Self-efficacy, coping skills, mindfulness	GSE; MOCS-A; CAMS
Berk et al. (2019)	Self-compassion, positive mental health; mindfulness; caregiver self esteem	12-item form of the Self-Compassion questionnaire; MHC-SF; FFMQ; CRA-SE (Care-Derived Self Esteem subscale)
Brinie et al. (2010)	Mindfulness	MAAS
Cheung et al. (2020)	Mindfulness	FFMQ-SF
Drossell, Fisher & Mercer (2011)	Coping	WoC-R, Social support subscale; WoC-R, problem focussed subscale
Hearn, Cotter & Finlay (2019)	Mindfulness	FFMQ
Ho et al. (2016)	Mindfulness	FFMQ
Hoppes et al. (2012)	Hope, optimism, mindfulness	State Hope Scale; 10-item Life Orientation Test-Revised; 14-item Freiburg Mindfulness Inventory
Hou et al. (2014)	Mindfulness, self-compassion	FFMQ; SCS-SF
Köhle et al. (2021)	Positive mental health, self-compassion, psychological flexibility, mastery, resilience	MHC-SF; AAQ-II; SCS-SF; BRS
Kor, Liu & Chien (2019)	Resilience, mindfulness	BRS; FFMQ-SF
Lloyd (2016)	Psychological flexibility, living to values	AAQ-II; VQ; FoReST-12
Losada et al. (2015)	Leisure	Leisure Time Satisfaction scale
Mallya & Fiocco (2019)	Self-esteem and mindfulness	RSES; FFMQ
Mosher et al. (2019)	Acceptance of illness	PEACE questionnaire
Oken et al. (2010)	Mindfulness, self-efficacy	MAAS; RMBPC
Paller (2015)	Pleasurable activities	ADLQ
Schellekens et al. (2017)	Mindfulness, self-compassion	FFMQ; SCS-SF
Stonnington et al. (2016)	Resilience, positive and negative affect, mindfulness	Connor- Davidson Resilience Scale; PANAS; MAAS
Theiling (2016)	Self-Compassion, Positive mental health	SCS-SF; MHC-SF
Ugalde (2018)	Problem-solving, mindfulness and preparedness.	Problem- Solving Inventory; CAMS; The Preparedness for Caregiving Scale
Van den Hurk et al. (2017)	Self-esteem	CRA-SE
Vranceanu et al. (2020)	Mindfulness & coping	CAMS; MOCS-A
Whitebird et al. (2013)	Perceptions of social support	Medical Outcomes Study Social Support Survey

Zarei (2018)	Self-compassion	SCS

Note. GSE: General self-efficacy scale; MOCS-A: Measure of current status; CAMS: Cognitive and affective mindfulness scale; MHC-SF: The Dutch Mental Health Continuum Short Form; FFMQ: Five-facet mindfulness questionnaire; CRA-SE: The Care-Derived Self-Esteem of the Caregiver Reaction Assessment ; MAAS: Mindful attention and awareness scale; SCS: self-compassion scale; AAQ-II: Acceptance and Action Questionnaire - II; SCS-SF: self-compassion scale- short form; BRS: Brief resilience scale; VQ: Values questionnaire; FoReST-12: Flexibility of Responses to Self-Critical Thoughts Scale; RMBPC: Revised Memory Problem and Behavior Checklist; ADLQ: Activities of daily living questionnaire; PANAS: positive and negative affect scale; WoC-R: Ways of Coping Checklist- revised.

Quality Assessment

A summary table of the quality assessment can be found in Appendix C. Overall, the percentage agreement between the reviewers was 90%. Following the quality assessment, the majority of studies were rated as 'very good' (*n*= 15; 60%) or 'good' (*n*=9; 36%) with only one study being rated as 'fair' (4%). Overall, the quality of reporting in the included studies was generally high, however, many studies failed to report whether they adequately captured any adverse effects of any of the interventions. This is noteworthy, as previous research has shown that the rates of adverse effects of psychotherapy range from 3-15% (Linden, 2013), and as such, adverse events may be likely to occur during the interventions.

Similarly, it was not always clear whether the presence of confounders had been fully considered by many of the included studies. Although many of the studies listed the demographic differences between or within the groups, they did not label them as potential confounders nor accounted for them in their subsequent analyses. In the RCTs, the omission of this information meant that it was not always possible to discern whether the control and intervention groups were truly comparable. In the non-RCTs the potential for confounding may be higher due to the lack of randomisation (Grimes & Schultz, 2002) and consequently, the lack of clarity surrounding confounding may pose a considerable threat to the validity of the findings (Munkholm et al., 2020).

External validity could also have been improved with further consideration of the representativeness of the sample. Internal validity was generally rated highly, however, as a large proportion of the studies were non-randomised controlled trials, improvements on this axis could have been achieved through the inclusion of factors such as randomisation and blinding. Similarly, in the RCTs it was not always clear how participants had been

randomised or whether the participants or researchers were blinded. Therefore, further detail relating to these procedures would have improved the study quality.

Out of the included studies, only four reported having adequate power. Ten of the studies did not report their power calculation, making it unclear whether they achieved adequate power, and fourteen studies reported being underpowered. One reason for this is likely to be the fact that many of the included studies were feasibility or pilot trials, which do not aim to achieve full statistical power (Julious, 2005). Some studies also reflected on the fact that the limited evidence base meant that it was not possible for them to include a power calculation and hoped instead that their study would enable others to calculate power in future trails of interventions in this area.

In the studies reporting the fact they were unpowered, difficulties with recruiting individuals from the target population was cited as the most common reason for limited sample sizes. Attrition was also identified as a limiting factor for recruitment, however, as many of the studies analysed data on an intention-to-treat basis, non-completers were still accounted for in the overall findings which may have reduced the impact of this factor.

An accurate calculation of the sample size needed to achieve adequate statistical power is an essential part of conducting valid research as it enables the researchers to have confidence in their ability to observe an effect of an intervention if it is present (Ahn & Seo, 2007). The absence of a power calculation has even been argued to be unethical (Lee & Kang, 2015). As such, due to the large proportion of studies either not reporting their power calculations, or being knowingly underpowered, the findings of this meta-analysis should be interpreted cautiously.

Meta-analysis

Of the 25 studies included in the meta-analysis, two studies were identified as using the same sample and as such, in line with the assumptions of independence required for meta-analysis, one study was subsequently excluded (Thieling, 2016). Two studies (Cheung et. al., 2020; Köhle et. al., 2021) included data from two active independent sub-groups and as such, these data were entered as four separate studies. Consequently, data from a total of 26 intervention studies were analysed. Combined outcomes were computed for twelve of the studies (Ugalde, 2018; Drossell, Fisher & Mercer, 2011; Hoppes et al. 2012; Hou et al. 2014; Stonnington et al., 2016; Schellekens et al., 2017; Van den Hurk et al., 2017; Vranceanu et al., 2020; Bannon et al., 2020; Brinie et al., 2010; Köhle et. al., 2021; Lloyd, 2016) due to the reporting of multiple relevant outcomes.

There was a significant positive small-sized effect of the interventions and positive outcomes (d= 0.321; 95% CI [0.130-0.513]; z= 3.283, p= .001). As expected, there was evidence of significant heterogeneity indicating the presence of a moderate amount of variance between studies (Q(25)= 77.133, p< .000 , I^2= 67.588, T^2= .155). Effect sizes ranged from d= -0.024 to 3.953 (Figure 2). As there was evidence of a moderate level of heterogeneity, potential sources of variance were examined using moderator analyses.

Figure 2.

Forest plot of studies included in the meta-analysis

Interventions and positive outcomes k = 26

Study name	Subgroup within study	Outcome	Std diff in means	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value	Total
Bannon et. al. (2020)	Recovering together	Combined	0.354	0.521	0.272	-0.667	1.376	0.680	0.497	17
Berk et. al. (2019)	TANDEM	Combined	0.287	0.350	0.122	-0.399	0.972	0.819	0.413	15
Birnie et al. (2010)	MBSR	MAAS	0.520	0.295	0.087	-0.058	1.097	1.763	0.078	21
Cheung et. al. (2020)	MBCT	FFMQ	0.624	0.270	0.073	0.094	1.153	2.307	0.021	26
Cheung et. al. (2020)	MBSR	FFMQ	0.157	0.260	0.068	-0.352	0.667	0.605	0.545	27
Drossel, Fisher & Mercer (2011)	DBT	Combined	0.494	0.280	0.078	-0.055	1.043	1.764	0.078	24
Hearn, Cotter & Finlay (2019)	Breathworks	FFMQ	0.746	0.304	0.093	0.149	1.343	2.451	0.014	55
Ho et. al. (2016)	MBSR	FFMQ	3.953	0.509	0.259	2.955	4.950	7.767	0.000	20
Hoppes et. al. (2012)	MBSR	Combined	0.519	0.382	0.146	-0.230	1.267	1.359	0.174	11
Hou et. al. (2014)	MBSR	Combined	0.059	0.168	0.028	-0.270	0.387	0.350	0.727	141
Kohle et. al. (2021)	Hold on AF	Combined	-0.029	0.166	0.028	-0.356	0.297	-0.177	0.860	70
Kohle et. al. (2021)	Hold on PF	Combined	0.123	0.170	0.029	-0.210	0.456	0.725	0.469	67
Kor, Liu & Chien (2019)	MBCT	BRS	0.042	0.322	0.104	-0.589	0.673	0.131	0.896	36
Lloyd (2016)	ACT	Combined	-0.145	0.524	0.274	-1.172	0.882	-0.277	0.782	18
Losada et. al. (2015)	ACT	Leisure	0.668	0.215	0.046	0.248	1.089	3.113	0.002	135
Mallya & Fiocco (2019)	MBSR	Self-esteem	0.324	0.269	0.072	-0.203	0.850	1.205	0.228	33
Mosher et. al. (2019)	ACT	PEACE	0.067	0.195	0.038	-0.316	0.449	0.342	0.732	50
Oken et. al. (2010)	MBCT	MAAS	-0.429	0.434	0.188	-1.279	0.422	-0.987	0.323	31
Paller (2015)	MBSR	ADL	-0.024	0.321	0.103	-0.654	0.605	-0.076	0.939	20
Schellekens et. al. (2017)	MBSR	Combined	0.066	0.323	0.104	-0.567	0.698	0.204	0.838	44
Stonnington et. al. (2016)	MBRT	Combined	-0.061	0.327	0.107	-0.703	0.580	-0.188	0.851	18
Ugalde (2018)	Study specific	Combined	0.254	0.355	0.126	-0.442	0.949	0.715	0.475	13
Van den Hurk et. al. (2017)	MBSR	Combined	-0.240	0.394	0.155	-1.012	0.533	-0.608	0.543	16
Vranceanu et. al. (2020)	Recovering together	Combined	0.424	0.270	0.073	-0.106	0.953	1.568	0.117	58
Whitebird et. al. (2013)	MBSR	Social support	0.351	0.229	0.052	-0.098	0.800	1.532	0.125	78
Zarei et. al. (2018)	MBCT	SCS	0.413	0.364	0.132	-0.299	1.126	1.137	0.255	26
			0.321	0.098	0.010	0.129	0.513	3.277	0.001	1070

Std diff in means and 95% CI — scale: -2.00, -1.00, 0.00, 1.00, 2.00. Favours A / Favours B.

Meta Analysis

Moderator Analyses

Age. The meta-regression of the influence of age showed that there were no significant age-related differences in the effects of interventions on positive outcomes ($Q(1)$= 012, β= -.008 ,p= .727, 95% CIs [-0.050, 0.035], z= -0.35; Appendix E). It can therefore be concluded that the magnitude of effects did not vary as a result of the participant's age.

Gender. The meta-regression on the influence of participant gender showed that there were no significant gender-related differences in the effects of interventions on positive outcomes ($Q(1)$= 1.13, β= .009 ,p= .287, 95% CIs [-0.007, 0.025], z= 1.06; Appendix E). It can therefore be concluded that the magnitude of effects did not vary as a result of the participant's gender.

Diagnosis of person receiving care. Of the 26 studies, three studies involved caregivers of people with acquired brain injuries, six involved caregivers of people with cancers, eleven involved caregivers of people with dementia and six involved 'other'

diagnoses. This subgroup analysis revealed that studies involving participants who cared for people with ABI (*d*= 0.313; 95% CI [-0.115, 0.740]), Cancer (*d*= 0.080; 95% CI [.-0.095, 0.256], dementia (*d*= 0.535; 95% CI [0.012, 0.968]) or 'other' (*d*= 0.253; 95% CI [0.020, 0.486]) did not differ significantly from each other in terms of the magnitude of the effect of the interventions (*Q*(3)= 4.553, *p*= .209).

Intervention type. Out of the 26 studies, ten related to MBSR, four MBCT, three ACT and nine related to mixed or study specific interventions. The subgroup analysis revealed that studies utilising each of the aforementioned interventions (MBSR; *d*= 0.486; 95% CI [0.031, 0.940]; MBCT; *d*= 0.230; 95% CI [-0.198, 0.658]; ACT; *d*= 0.028; 95% CI [-0.213, 0.767]; mixed; *d*= 0.214; 95% CI [0.044, 0.384]) did not differ significantly from each other in terms of the magnitude of the effect of the interventions (*Q*(3)= 1.219, *p*= .749).

Outcome type. Out of the 26 studies, six captured outcomes solely on mindfulness, eight on 'other' outcomes, and twelve were combined measures of effect which were not included in this moderator analysis. The subgroup analysis revealed that studies capturing data on mindfulness (*d*= 0.872; 95% CI [0.040, 1.705]), 'other' (*d*= 0.307; 95% CI [0.129, 0.486]) or 'combined' (*d*= 0.104; 95% CI [-0.044, 0.252]) did not differ significantly from each other in terms of the magnitude of the effect of the interventions (*Q*(2)= 5.502, *p*= .064).

Publication Bias

Rosenthal's (1979) fail-safe *N* analyses found that 183 studies with null results would be required to reduce the significance of the effects to more than *p*= .05. The funnel plot (Figure 3) also shows relative symmetry, and a trim and fill test resulted in ten studies being trimmed. Ten studies were imputed to the right of the mean. Egger's regression test was also non-significant (*t*(24)= 1.557, *p*= .132). These analyses indicate that the risk of publication bias in this review is low.

Figure 3.

Funnel plot to assess publication bias

Funnel Plot of Standard Error by Std diff in means
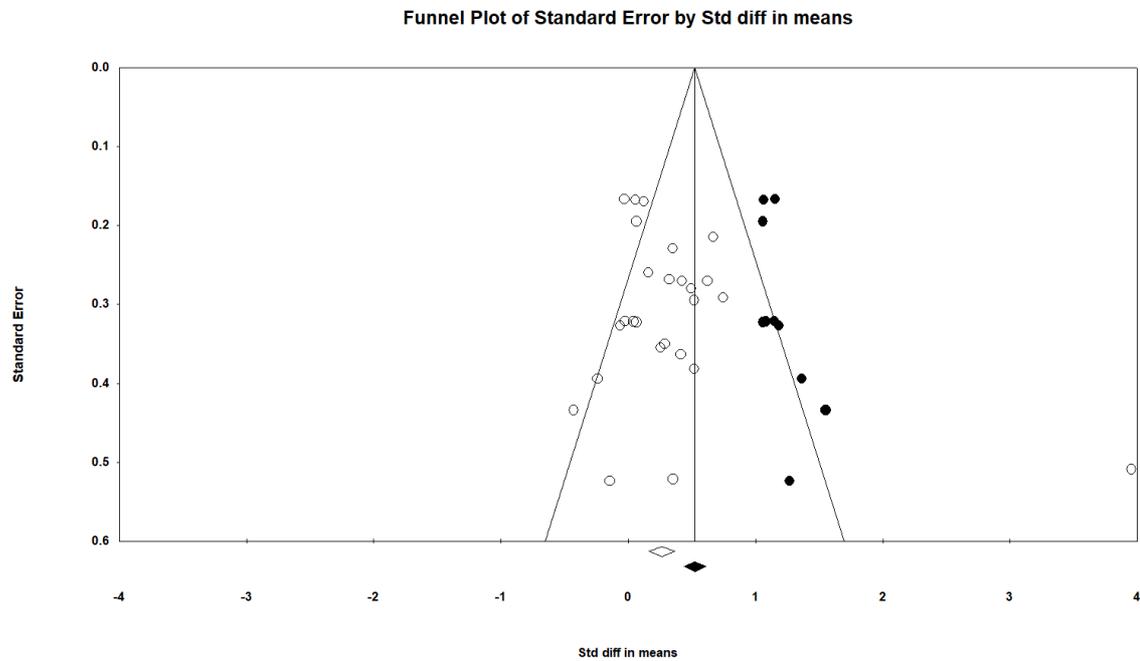
Note. White dots indicate included studies, black dots indicate studies imputed by the trim and fill test.

Discussion

To the authors knowledge, this is the first meta-analysis to quantify the effectiveness of third-wave interventions on positive outcomes for caregivers. A positive, small-sized overall effect was found, supporting the hypothesis that third wave therapies are effective for increasing positive outcomes in caregivers. These findings are consistent with similar studies on the effectiveness of other therapeutic modalities in this population (e.g. CBT; Hopkinson et al., 2019), which similarly report small-to-medium effect sizes. This suggests that third wave therapies may be as effective in caregiver populations as more commonly used therapies such as CBT.

Although moderate levels of heterogeneity were found between the studies, this variance was not explained by the moderators. That is, neither age, gender, diagnosis of the person receiving care, outcome index nor intervention type accounted for the heterogeneity. Between sample heterogeneity is not uncommon in meta-analyses of treatment effects (Riley, Higgins & Deeks, 2011). Indeed, although heterogeneity may be due to genuine, meaningful variance across the data sets (e.g. interventions, outcomes) it may also be reflective of biases inherited from the included studies which may not be truly meaningful (Ioannidis, 2008). As such, although it is preferable to identify the causes of heterogeneity (Thompson, 1994), it is not always possible (Higgins & Thompson, 2002). Consequently, there are likely to be alternative moderators that account for this unexplained variance which future research could investigate.

One possible moderator could be the presence of clinically significant symptomatology, as it is plausible that the effects of psychological interventions may differ depending on whether they had been conducted with clinical or non-clinical caregiver populations. This idea is supported by evidence from other interventions (e.g. activity for depressive symptoms; Rebar et al., 2015) whereby the effectiveness of the intervention is reduced in non-clinical populations. One explanation for this may be a 'floor' effect for example, as clinical populations may have higher scores on measures of anxiety than non-clinical populations, there is greater room for an improvement in scores (Rebar et al., 2015). However, in contrast, reviews on the effectiveness of ACT have found there to be little difference in the effectiveness of the intervention on clinical and non-clinical samples (Thompson et al., 2021) potentially owing to the transdiagnostic nature of ACT. As such, it is unclear whether the inclusion of both clinical and non-clinical samples in this review may have impacted on the heterogeneity of findings. Future research would benefit from exploring

other potential moderators that may impact the effectiveness of interventions in caregiver populations.

Strengths and limitations

The findings of this meta-analysis, although novel, should be considered in light of several strengths and limitations. One potential limitation of the meta-analysis may be the use of synthetic variables calculated by averaging the effect size for studies reporting multiple outcome measures. Although this method is commonly utilised in meta-analysis (Card, 2015), it assumes significant levels of correlation between the combined variables. The impact of this is twofold. Firstly, the use of combined variables limited the extent to which the moderating effect of outcome type could be examined (e.g. mindfulness vs. self-compassion). Only mindfulness could be meaningfully disaggregated from the outcome types utilised by the included studies, which meant that the impact of other singular outcomes could not be explored. Future studies that focus on the effectiveness of interventions to improve specific positive outcomes (e.g. self-compassion) would be beneficial in increasing awareness of the specific effects of interventions.

Secondly, although a high level of association was assumed between the outcomes, it may be that there were higher levels of variance between the combined measures than previously expected. For example, in the case of measures of psychological flexibility, evidence suggests that there is a conceptual distinction between flexibility and inflexibility, with one being more closely related to positive outcomes than the other (Rogge et al., 2019). This may have meant that other methods of combining multiple outcomes across studies may have been more appropriate, and the utilisation of this method may have led to an over-estimation of variance. Moreover, this may also have contributed to the moderate levels of unexplained heterogeneity in the sample.

A further limitation may be the inclusion of inadequately powered studies. As previously stated, a large proportion of the included studies were pilot or feasibility trails and only four of the studies achieved adequate power. The inclusion of small studies is common in meta-analyses, however their inclusion can introduce additional bias to the data, potentially as the result of methodological flaws (Turner, Bird & Higgins, 2013). Consequently, the appropriateness of including small-scale research has been questioned (e.g. Kjaergard, Villumsen & Gluud, 2001). Advocates for the inclusion of small studies cite the importance of including all levels of data (e.g. Turner et al., 2009). A recent review found that small studies contribute relatively little to meta-analyses so long as at least two adequately powered studies are included (Turner, Bird & Higgins, 2013). As such, although the findings of the present study should be interpreted with caution due to the inclusion of underpowered studies, it is unlikely that their inclusion contributed significantly to the results.

In terms of strengths, this study provides a novel examination of the effectiveness of third wave therapies on positive outcomes for adult caregivers. It was conducted in adherence with PRISMA guidelines and utilised systematic search terms which were informed by the PICO framework. As such, it is transparent in its methodology and easily replicable.

The absence of any evidence of publication bias is also advantageous, as it reduces the risk that the findings of the meta-analysis have been over-estimated. Although the inclusion of grey literature is controversial, its inclusion in the present study may have been beneficial in reducing the risk of bias relating to the over publication of studies with significant results.

Clinical Implications

As discussed previously, this meta-analysis found that third wave interventions had a small, positive effect on positive outcomes for caregivers. As this is similar to the effects of more established therapies, it is suggestive of the fact that third wave interventions are a possible effective alternative to traditional interventions in caregiver populations. Moreover, when combined with evidence supporting the effectiveness of third wave interventions on reducing negative symptomatology, these findings suggest that third wave interventions are effective in both increasing positive outcomes and reducing negative outcomes. However, as this meta-analysis focussed solely on immediate post-intervention outcomes, no conclusions as to the effectiveness of third-wave interventions in increasing positive outcomes in the long-term can be drawn.

It is also important to note that there was no significant effect of intervention type as this may suggest that there is an underlying mechanism underpinning the effectiveness of third wave interventions, which may be a focus for future research. However, this finding also potentially provides evidence for the validity of evidence regarding the 'dodo bird' verdict of psychotherapy, originally coined by Smith and Glass (1977) which argues that there is no clear support for the use of one therapy over the other. This view argues, amongst other factors, that the dyadic and relational nature of all therapies means that maintaining intervention 'purity' is problematic (Budd & Hughes, 2009). As such, although there are conceptual and practical differences between the therapies that fall under the banner of third wave, it may be that their effectiveness is based more on relational or 'common' factors rather than the specific techniques used in the interventions (Budd & Hughes, 2009)

Future Research

Of the interventions published to date, most have been completed with females between the ages of 55-65. Consequently, the applicability or effectiveness of third wave

interventions for those who identify as genders other than female, or those either at the younger or older age ranges is unclear and it would be beneficial for future research to examine the effectiveness of interventions with these populations. Similarly, as this meta-analysis focused on the short-term effectiveness of third wave therapies, the longevity of their effectiveness on positive outcomes may also be a prudent area for future research.

It is also noteworthy that, although some of the included studies integrated aspects of CFT, none of the studies used this as the main intervention. Dispositional levels of self-compassionate action have been found to mitigate against stress related to caregiving, with self-compassion being a significant moderator between the relationship between caregiver stress and depression (Hsieh, Yu & Chen, 2019). Self-compassion has also been highlighted as a potentially important intervention target for older adult caregivers (Murfield, Moyle & O'Donovan, 2020). As such, future research into the effectiveness of compassion-based approaches in this population would be advantageous, as would meta-analyses focussing specifically on capturing the effectiveness of interventions in increasing self-compassion in caregivers. Similarly, as there is relatively little known about the role of compassion in aspects of the caregiving experience, exploratory research on the role of compassion would be beneficial in increasing understanding on useful targets for intervention.

Conclusions

In conclusion, this meta-analysis provides evidence that third wave interventions have a small-sized positive effect on positive outcomes for caregivers. There was a moderate level of heterogeneity between the studies which remained unexplained after moderator analyses of age, gender, intervention type, outcome type and caregiver population. Research regarding other potential moderators, such as the presence of clinical symptomatology, is recommended.

These findings, combined with research suggesting that third wave interventions are effective in reducing negative symptoms in this population, suggests that third wave interventions may be a robust alternative to more traditional therapies in caregiver populations. Moreover, through focussing on positive outcomes rather than solely negative symptoms, they may have the additional benefit of addressing a more holistic perspective of the caregiver experience.

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Appendices

Appendix A	Example data extraction sheet
Appendix B	Downs and Black checklist (Downs & Black 1998)
Appendix C	Quality assessment ratings
Appendix D	Meta-regressions

Appendix A: Example data Extraction form

Table A1.

Data extraction form

Review title or ID	

General Information

Date form completed	
Publication type *(e.g. full report, abstract, letter)*	
Notes:	

Characteristics of included studies

Methods

	Descriptions as stated in report/paper	Location in text or source
Aim of study *(e.g. efficacy, equivalence, pragmatic)*		
Design*(e.g. parallel, crossover, non-RCT)*		
Notes:		

Participants

	Description *Include comparative information for each intervention or* *comparison group if available*	Location in text or source
Population description *(from which study* *participants are drawn)*		
Setting *(including location and* *social context)*		
Total no. randomised *(or total pop. at start of* *study for NRCTs)*		
Age		
Sex		
Race/Ethnicity		
Diagnosis of person **receiving care**		
Other relevant **sociodemographics**		
Notes:		

Intervention

	Description as stated in report/paper	Location in text or source
Group name		
No. randomised to group *(specify whether no. people or clusters)*		
Description		
Duration of treatment period		
Timing *(e.g. frequency, duration of each episode)*		
Delivery *(e.g. mechanism, medium, intensity, fidelity)*		
Notes:		

Outcomes

	Description as stated in report/paper	Location in text or source
Outcome name		
Time points measured *(specify whether from start or end of intervention)*		

Outcome definition *(with diagnostic criteria if relevant)*		
Power *(e.g. power & sample size calculation, level of power achieved)*		
Notes:		

Data and analysis

	Description as stated in report/paper	**Location in text or source** *(pg & ¶/fig/table/other)*
Comparison		
Outcome		
Subgroup		
Time point *(specify from start or end of intervention)*		
Post-intervention or change from baseline?		

	Intervention	**Comparison**	

Results	Mean	SD *(or other variance, specify)*	No. participants	Mean	SD *(or other variance, specify)*	No. participants	
(for studies without a control group, use the pre-post scores)							
Any other results reported *(e.g. mean difference, CI, P value)*							
Statistical methods used and appropriateness of these *(e.g. adjustment for correlation)*							
Reanalysis required? *(calculate effect size?)*	☐ Yes	☐ No	☐ Unclear				
Reanalysis possible?	☐ Yes	☐ No	☐ Unclear				
Reanalysed results							
Notes:							

Appendix B: Downs and Black Checklist (Downs & Black, 1998)

Appendix

Checklist for measuring study quality

Reporting

1. *Is the hypothesis/aim/objective of the study clearly described?*

yes	1
no	0

2. *Are the main outcomes to be measured clearly described in the Introduction or Methods section?*
   If the main outcomes are first mentioned in the Results section, the question should be answered no.

yes	1
no	0

3. *Are the characteristics of the patients included in the study clearly described ?*
   In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.

yes	1
no	0

4. *Are the interventions of interest clearly described?*
   Treatments and placebo (where relevant) that are to be compared should be clearly described.

yes	1
no	0

5. *Are the distributions of principal confounders in each group of subjects to be compared clearly described?*
   A list of principal confounders is provided.

yes	2
partially	1
no	0

6. *Are the main findings of the study clearly described?*
   Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below).

yes	1
no	0

7. *Does the study provide estimates of the random variability in the data for the main outcomes?*
   In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0

8. *Have all important adverse events that may be a consequence of the intervention been reported?*
   This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided).

yes	1
no	0

9. *Have the characteristics of patients lost to follow-up been described?*
   This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.

yes	1
no	0

10. *Have actual probability values been reported(e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?*

yes	1
no	0

External validity
All the following criteria attempt to address the representativeness of the findings of the study and whether they may be generalised to the population from which the study subjects were derived.

11. *Were the subjects asked to participate in the study representative of the entire population from which they were recruited?*
    The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant

population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.

yes	1
no	0
unable to determine	0

12. *Were those subjects who were prepared to participate representative of the entire population from which they were recruited?*
The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.

yes	1
no	0
unable to determine	0

13. *Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?*
For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.

yes	1
no	0
unable to determine	0

Internal validity - bias
14. *Was an attempt made to blind study subjects to the intervention they have received ?*
For studies where the patients would have no way of knowing which intervention they received, this should be answered yes.

yes	1
no	0
unable to determine	0

15. *Was an attempt made to blind those measuring the main outcomes of the intervention?*

yes	1
no	0
unable to determine	0

16. *If any of the results of the study were based on "data dredging", was this made clear?*
Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.

yes	1
no	0
unable to determine	0

17. *In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls ?*
Where follow-up was the same for all study patients the answer should yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.

yes	1
no	0
unable to determine	0

18. *Were the statistical tests used to assess the main outcomes appropriate?*
The statistical techniques used must be appropriate to the data. For example non-parametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0
unable to determine	0

19. *Was compliance with the intervention/s reliable?*
Where there was non compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.

yes	1
no	0
unable to determine	0

20. *Were the main outcome measures used accurate (valid and reliable)?*

For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.

yes	1
no	0
unable to determine	0

Internal validity - confounding (selection bias)

21. *Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?*

For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case-control studies where there is no information concerning the source of patients included in the study.

yes	1
no	0
unable to determine	0

22. *Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?*

For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.

yes	1
no	0
unable to determine	0

23. *Were study subjects randomised to intervention groups?*

Studies which state that subjects wereran-domised should be answered yes except where method of randomisation would not ensure random allocation. For example alternate allocation would score no because it is predictable.

yes	1
no	0
unable to determine	0

24. *Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?*

All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.

yes	1
no	0
unable to determine	0

25. *Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?*

This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In non-randomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.

yes	1
no	0
unable to determine	0

26. *Were losses of patients to follow-up taken into account?*

If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.

yes	1
no	0
unable to determine	0

Power

27. *Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?*

Sample sizes have been calculated to detect a difference of x% and y%.

	Size of *smallest* intervention group	
A	$<n_1$	0
B	n_1-n_2	1
C	n_3-n_4	2
D	n_5-n_6	3
E	n_7-n_8	4
F	n_8+	5

Appendix C: Quality assessment ratings

Table A2.

Quality Assessment Ratings

Author	Reporting										External validity			Internal validity- bias							Internal validity- confounding						Power	Rating
	1	2	3	4	5	6	7	8	9	10	1	2	3	1	2	3	4	5	6	7	1	2	3	4	5	6	1	
Bannon et al. (2020)	G	G	G	G	R	G	G	G	G	G	G	R	G	R	R	G	G	G	G	G	G	G	G	G	G	G	R	Very Good
Berk et al. (2019)	G	G	G	G	R	G	G	R	G	R	G	R	G	R	G	G	G	G	G	G	G	G	R	R	R	G	R	Good
Brinie et al. (2010)	G	G	G	G	G	G	G	R	G	R	G	O	G	R	O	O	G	G	G	G	G	G	R	R	R	R	O	Good
Cheung et al. (2020)	G	G	G	G	G	G	G	G	G	G	G	O	G	G	G	G	G	G	G	G	G	G	G	G	G	G	O	Very Good
Drossell, Fisher & Mercer (2011)	G	G	G	G	R	G	G	G	G	G	R	R	G	R	G	G	G	O	G	G	G	G	R	R	R	G	R	Good
Hearn, Cotter & Finlay (2019)	G	G	G	G	R	G	G	G	G	G	R	R	G	R	G	G	G	G	G	G	G	R	R	G	G	G	G	Very Good
Ho et al. (2016)	G	G	G	G	R	G	G	G	G	G	O	G	G	R	G	G	O	G	G	G	G	R	R	R	G	G	O	Good
Hoppes et al. (2012)	G	G	R	G	R	G	G	R	R	R	R	G	G	R	G	G	O	G	G	G	G	R	R	R	G	R	R	Fair
Hou et al. (2014)	G	G	G	G	G	G	G	G	G	G	O	O	G	G	R	G	G	G	G	G	G	G	G	G	G	G	R	Very Good
Köhle et al. (2021)	G	G	G	G	G	R	G	G	G	G	O	G	G	O	O	G	G	G	G	G	G	G	O	G	G	G	R	Very Good
Kor, Liu & Chien (2019)	G	G	G	G	G	G	G	G	G	G	O	O	G	R	R	G	G	G	G	G	G	G	G	G	G	G	G	Very Good
Lloyd (2016)	G	G	G	G	G	R	G	G	G	G	G	G	G	O	O	G	G	O	G	G	G	G	O	O	O	G	R	Very Good
Losada et al. (2015)	G	G	G	G	G	G	G	R	G	G	O	O	G	O	G	G	G	G	G	G	G	G	G	O	R	G	O	Very Good
Mallya & Fiocco (2019)	G	G	G	G	G	G	G	R	G	G	O	G	G	G	G	G	G	G	G	G	G	G	O	O	O	G	G	Very Good
Mosher et al. (2019)	G	G	G	G	G	G	G	R	G	G	G	G	G	O	G	G	G	G	O	G	G	G	G	G	G	G	R	Very Good

Oken et al. (2010)																										Very Good
Paller (2015)																										Very Good
Schellekens et al. (2017)																										Very Good
Stonnington et al. (2016)																										Good
Theiling (2016)																										Good
Ugalde (2018)																										Very Good
Van den Hurk et al. (2017)																										Good
Vranceanu et al. (2020)																										Very Good
Whitebird et al. (2013)																										Very Good
Zarei (2018)																										Very Good

Note. Green = yes; Amber= Unclear; Red= No

Appendix D: Meta-regressions

Figure A1.

Meta-regression for Age

Regression of Std diff in means on Age
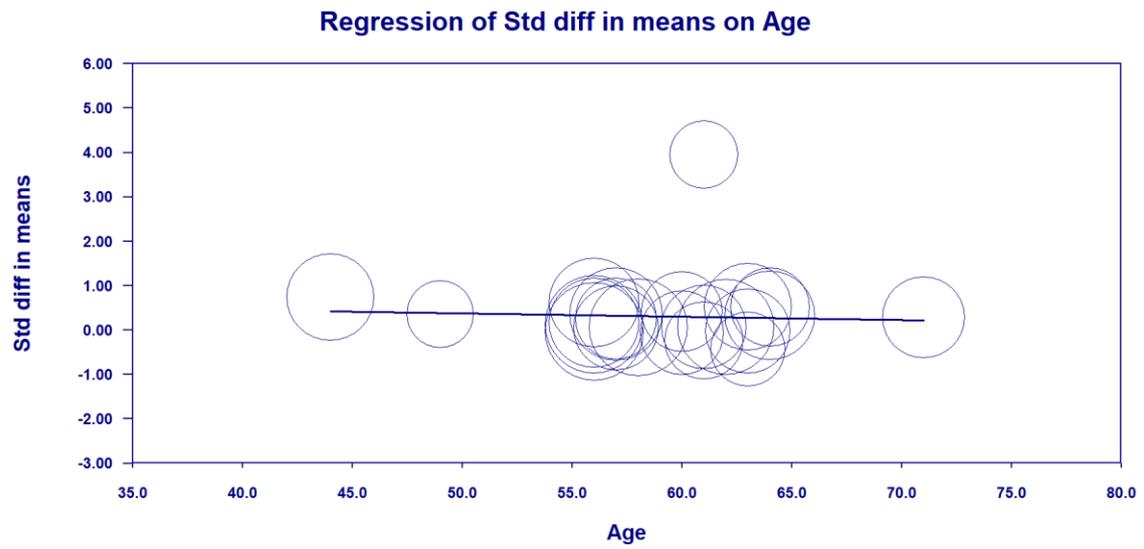
Figure A2.

Meta-regression for Gender

Regression of Std diff in means on %female
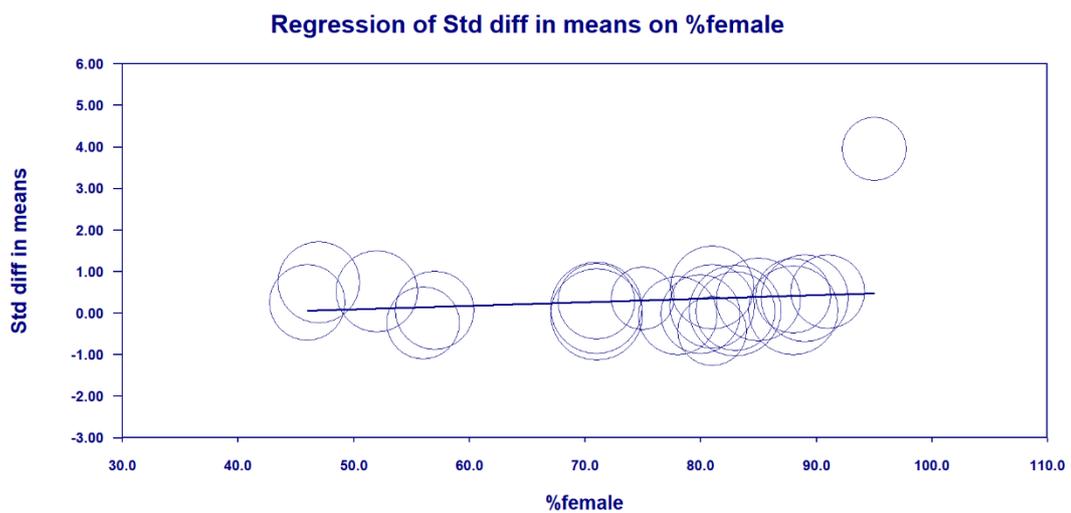
Note. Gender was operationalised using the percentage of female participants

Part II: Empirical Project

Compassion and the use of support by family caregivers of people with

dementia: An exploratory mixed-methods study

Abstract

Objectives

Providing care for a person with dementia (PwD) can have a significant impact on wellbeing. This may be mitigated by the effective use of support, however support use by this population is low. This study aimed to explore the role of compassion in decisions to utilise support.

Design

A convergent parallel mixed-methods design was utilised with both qualitative and quantitative data being merged and triangulated to inform findings.

Methods

A total of 51 caregivers of people with dementia completed the online survey. Of these, 45 (88%) were female, and the ages ranged from 44-79. The survey included measures of compassion, burden, attachment style and level of support use. Open-ended questions exploring participants perceptions of compassion were also included. Multinomial regression was conducted to examine the extent to which the independent variables (compassion, burden, attachment style) predicted membership to groups based on the level of support use. Qualitative data were analysed using template analysis with *a* priori themes. Data were merged and triangulated.

Results

Multinomial regression analyses revealed that none of the predictor variables were effective in predicting the level of support use ($p = .27$). Qualitative findings suggested that perceptions of compassion from others did impact decisions on whether to access support.

Conclusions

This study provides an exploration of the role of compassion in the experiences of caregivers of people with dementia who are making decisions regarding accessing support. The findings, although tentative, may advocate the need for the provision of compassionate, tailored support for caregivers of PwD.

Practitioner Points

- This study highlights the importance of compassionate and tailored support for caregivers of people with dementia.

- Findings suggest a potential role for interventions focussing on increasing self-compassion for caregivers however, future research is required to examine the applicability of such interventions in this population.

  Key words: 'compassion', 'caregivers', 'support use', 'dementia', 'alzhiemer's'

<center>**Introduction**</center>

In the UK, there are estimated to be 850,000 people living with dementia (Prince, 2014). Dementia is defined as an umbrella term for a number of degenerative neurocognitive disorders of which the main symptoms are a decline in cognitive or emotional abilities as a result of structural changes in the brain (American Psychiatric Association, 2013). The progressive nature of dementia means that the course of dementia often occurs over several years, with persons with dementia (PwD) often requiring increasing levels of support (Miranda-Castillo, Woods & Orrell, 2010). This responsibility often falls to informal caregivers, with approximately 80% of community-dwelling PwD in the UK being cared for by their loved ones in a non-professional capacity (Alzheimer's Society, 2014). As a result, dementia is considered to be a major public health concern, the physical and emotional consequences of which extend not only to those with dementia but also their caregivers (Vandepitte et al., 2016).

Over the last few decades, there has been a rapidly developing evidence base examining the impact of providing care for a PwD. In particular, the emotional impact of caregiving can be significant, with the most frequently reported consequences being depression, burden, loneliness, and general psychological distress (e.g., Pinquart & Sörensen, 2003). Moreover, this impact is disproportionate in comparison to other caregiver populations (Brodaty et al., 2005), particularly for caregivers who are spouses or daughters of the person receiving care (Kaspar et al., 2015).

One way to mitigate the emotional and practical impact of caregiving is through the effective use of support. Consequently, government policy in the UK is focused on the provision of support services to caregivers of PwD to enable them to remain in their caring roles for as long as they wish to do so (Department of Health, 2013). Additionally, a number

of interventions have been developed to support caregivers with the emotional challenges that may arise during their caregiver role and improve wellbeing (Parker, Mills & Abbey, 2008). Despite this, the use of support services by caregivers for PwD is low (see Brodaty et al., 2005; Toseland et al., 2002). Two factors that have been suggested as being central to the non-use of services for caregivers of PwD are lack of awareness of services and perceived lack of need (Brodaty et al., 2005). The ability to identify one's own need for support and being motivated to resolve this can be understood in terms of the concept of compassion (Gilbert, 2010). Compassion has been defined as "a sensitivity to suffering in self and others, with a commitment to try to prevent or alleviate it" (Gilbert, 2014, p. 19).

The role of compassion

There is a growing body of research on the role of compassion in various populations due to its links with mental health outcomes (Barnard & Curry, 2011). However, compassion does not exist as a unitary concept. Instead, it has been conceptualised as having three 'flows' (Gilbert, 2014). The term 'flow' of compassion refers to the dynamic reciprocal processing nature of compassion (Kirby, Day & Sagar, 2019). Therefore, compassion occurs within a social-interactional context (Gilbert, 2014) and can be directed from 1) self-to-other, 2) other-to-self, and 3) self-to-self (self-compassion). The interaction between these three flows can be both interdependent and independent, and some individuals may have difficulties with one flow but not the other (Kirby, Day & Sagar, 2019).

Self-compassion, in particular, has been highlighted as an important concept when it comes to research into caregiver populations (see Murfield, Moyle & O'Donovan, 2019). The term self-compassion refers to an individual's ability to be sensitive to one's own suffering and be motivated towards alleviating it (Gilbert, 2009). Self-compassion has been found to be amenable to intervention (Neff & Davidson, 2016). There is a growing evidence base

supporting the benefits of self-compassion interventions for professional caregivers of PwD

as a means of improving caregivers' ability to cope in their caregiving role and reducing

feelings of burden (e.g., Murfield, Moyle & O'Donovan, 2019). However, research into the

role of self-compassion for informal caregivers of PwD is in its infancy, and research is

required to further develop an understanding of its function and amenability to intervention in

this population. As such, developing an understanding of the role of self-compassion in

caregivers, particularly in those who may find it difficult to accept support, may assist

clinicians in identifying those who may benefit from interventions.

There is also a dearth of research examining the impact of compassion in a broader

sense. Aspects of compassion have been found to impact decisions made by healthcare

professionals on whether they access support in their roles (Egan et al., 2019). The ability to

practice self-compassion and perceptions of compassion from other members of the team are

highlighted as being particularly important (Egan et al., 2019). Other-to-self compassion has

been defined as the ability to identify and respond positively to offers of support from others

(Gilbert, 2014). The ability to detect compassionate support from others may be negatively

impacted by high levels of stress or burnout, both of which are particularly prevalent in

caregiver populations (Day & Anderson, 2011). Despite this, the role of other-to-self

compassion in caregivers of PwD has not previously been explored. If a relationship between

compassion and use of support in caregivers of PwD is identified, it may serve as a valuable

indicator for individuals who are at risk of under-utilising services and may indicate the need

for more pro-active provision of support.

Other factors in the utilisation of support

Although the extent to which compassion has a role in decisions to access support is

currently unclear, there is existing research into other factors that may influence the use of

support in caregiver populations. For example, levels of perceived burden have been found to be associated with the use of support in caregivers considering the use of respite services (Brodaty et al., 2005). Moreover, caregivers with high levels of burden are more likely to seek support, regardless of whether they are currently accessing it (Phillipson, Jones & Magee, 2014). Burden has also been found to be negatively associated with levels of self-compassion in caregivers of PwD (Lloyd et al., 2019) and, as such, may act as a confounding factor in any study exploring the impact of compassion on support use in this population. Consequently, burden was included in the present study as a potential predictor of support use.

A second factor that is known to impact the utilisation of support in other, non-caregiver populations is adult attachment style (Preil & Shamai, 1995; Moreira et al., 2003; Schmidt et al., 2012; Feeney, 2000). Attachment style refers to an individual's pattern of relating to and experiencing others, which develops throughout childhood through repeated experiences with attachment figures (Ognibene & Collins, 1998). These internal working models are carried on into adulthood and can influence many areas of both personal and interpersonal functioning (Ognibene & Collins, 1998). The presence of anxious or avoidant attachment styles has been linked to differences in areas such as emotional wellbeing (Merz & Consedine, 2009), coping style (Collins, 1996), and ability to seek support (Simpson, Rholes & Nelligan, 1992), compared to those with secure attachment styles. Like burden, attachment style has also been linked to elements of compassion (Wei et al., 2011; Gilbert, 2014). Consequently, a measure of adult attachment style as also included in the present study as a potential predictor of support use.

Present Study

As a result of the potential role that aspects of compassion may have in decisions to access support by caregivers of PwD, this exploratory study aimed to provide insight into the

role of compassion in decisions to use support by caregivers of PwD. As previously mentioned, the limited existing evidence base also suggests that other factors such as the presence of high levels of burden and attachment style may also play a role in caregiver's decisions to access support. Consequently, burden and attachment style were included in the present study to examine their role in decision making. The present study employed a mixed-methods approach as this was deemed to be appropriate for the purposes of this exploratory research. By mixing the data types, a more complete understanding of the role of compassion in the use of services for caregivers of PwD may be developed. A further justification of the use of mixed-methods in this instance is the utility of mixed-methods research in balancing the strengths and weaknesses of both qualitative and quantitative approaches (e.g., Jick, 1979). For example, it allows for both the exploration and examination of the role of compassion in caregiver's decisions to access support, which would not be feasible if the study employed solely quantitative or qualitative methodology.

Aims

The primary aims of this study were to examine whether there any significant differences between the aspects of compassion (self-self, other-self, or self-other), burden or attachment style in caregivers accessing different amounts of support. Of particular interest are the aspects of self-compassion and other-to-self compassion and whether these concepts are able to predict the use of support in caregivers of PwD. A further aim is to explore the ways in which caregivers perceive receiving support from others and whether this impacts their decision to accept or access support.

Hypotheses

1. Participants with high levels of self-compassion will access more support than those reporting low levels of self-compassion.

2. Participants who perceive others as being low in compassion will access less support than those perceiving others as being high in compassion.

3. Self-compassion, other-to-self compassion, attachment style, and level of burden will predict membership to groups based on the amount of support utilised (low, medium, high). Self-compassion, other-to-self compassion, and level of burden are expected to predict high levels of support use and attachment style is expected to predict low levels of support use.

Method

Design overview

A convergent parallel mixed-methods design was utilised in which qualitative and quantitative data were collected in parallel, analysed separately, and then merged. In this study, surveys were used to examine the relationship between aspects of compassion (self-compassion and compassion from others) and the use of support in caregivers of PwD. For the purposes of this study, support is defined as being either informal (e.g., provided by family, friends) or formal (e.g., NHS services, charities) in order to capture all aspects of the caregiver experience. In addition, open-ended questions were embedded into the survey with the aim of exploring participant's experiences of being offered support as well as factors considered in their decisions to access support. Once the quantitative and qualitative data had been collected and analysed, both data types were merged and assessed for convergence/divergence using triangulation.

Ethics

Ethical approval for the study was obtained from the University of Sheffield Research Ethics Committee (see Appendix A).

Participants

A total of 51 participants completed the survey. Of these, 45 (88%) were female, and the ages ranged from 44-79. Seventeen of these participants also contributed to the qualitative aspect of the study. Table 1 provides a full summary of participant characteristics.

Table 1

Summary of Participant Characteristics

Variable	*n* (%), Mean (SD)
Age (range 44-79)	N/A, 63 (9.45)
Sex	
Male	6 (12)
Female	45 (88)
Other	0
Ethnicity	
White	48 (94)
Indian	2 (4)
Other	1 (2)
Relationship status	
Married/ living with an intimate other	40 (78)
Separated/divorced	5 (10)
Never married	6 (12)
Widowed	0
Length of time spent as a caregiver (range 8 months-20 years)	N/A, 4.8 years (3.61)
Diagnosis	
Alzheimer's	22 (43)
Vascular	12 (24)
Frontotemporal	2 (4)
Young onset	2 (4)
Posterior Cortical Atrophy (PCA)	1 (2)
Parkinson's dementia	1 (2)

Mixed	8 (16)
Unsure	3 (6)
Physical health	
Excellent	1 (2)
Very good	34 (65)
Fair	15 (29)
Poor	1 (2)

Participants eligible for inclusion were defined as being self-identified informal adult caregivers of an individual who has received a formal diagnosis of dementia. Table 2 provides a summary of the exclusion criteria. Similar to existing research in the area (e.g., Stirling et al., 2010), participants are eligible for inclusion if they self-identify as being the primary caregiver for the PwD and provide five or more hours of support a week (Ablitt, Jones & Muers, 2008; Lloyd et al., 2018). Informal caregivers were defined as being individuals who have an existing social relationship with the PwD (e.g., friend, partner, spouse, child) and who are providing care in a non-professional capacity. Due to the exploratory nature of this study, a range of dementia subtypes (e.g., Alzheimer's, Vascular) were included. Similarly, caregivers providing a range of support for the PwD were also included (e.g., emotional, practical, physical care). This was done with the aim of increasing the richness of data, thus enabling a more developed exploration of a caregiver's experiences.

Table 2

Exclusion criteria

They are a caregiver for someone who does not have a diagnosis of dementia.
They are under 18 years of age.
Their caring role is in a professional capacity (e.g., nurses, care assistants, etc.).

They are not involved in actively caring for someone with dementia, although they may have done so in the past.

They provide less than 5 hours of support for the PwD.

They do not self-identify as the primary caregiver for the PwD.

A priori power analysis was conducted to determine the sample size required to prevent type II errors. Assuming a medium effect size of $f^2 = 0.15$ (based findings from Lloyd et al., 2018), a significance level of alpha = 0.05, and five variables of interest, a total sample size of 92 participants was required to achieve 80% power.

Recruitment and procedure

A convenience sampling strategy was used to recruit participants over a large geographical area. Data collection took place from August 2020- April 2021. Recruitment was conducted over various platforms. Firstly, Google searches were conducted to identify charities within the Yorkshire region that run caregiver support groups or events. Once identified, relevant organisations were contacted and asked whether they would be willing to participate in the recruitment of participants through the circulation of an online advertisement on their social media (an example of the email sent to charities can be found in Appendix B). Unfortunately, recruitment occurred during the COVID 19 pandemic, which resulted in the closure of many businesses, including charities. As a consequence, none of the contacted charities were able to support recruitment during this time, and no participants were recruited using these methods.

A second area utilised for the recruitment of participants was social media and online support forums for caregivers of PwD. Internet searches were conducted using Google and Facebook to identify relevant platforms. Once identified, an online advertisement was posted

on the various platforms, which contained a summary of the research, the researcher's contact details and a link to the survey and consent forms (Appendix C). Approximately 20% of participants were recruited either via social media or online support groups.

Finally, the study was entered onto an online self-registration service named Join Dementia Research (JDR). JDR enables volunteers with dementia or their caregivers to register their interest in participating in research in this area and to be matched to any relevant studies. The JDR is funded by the Department of Health and works in partnership with various charities such as the Alzheimer's Society and Alzheimer's Research UK. A lay summary of the study, which was created in line with INVOLVE guidelines, was provided (Appendix D), alongside the link to the survey. Approximately 55% of participants were recruited via the JDR. The remaining 25% of participants did not report the source of recruitment.

The survey was accessed through a web link in the online advertisement hosted by Qualtrics. Participants were provided with a participant information sheet (Appendix E) and consent form (Appendix F), which screened participants for eligibility. Details of how to request a paper copy of the survey were also included in the advertisement. However, due to the University closures caused by the COVID-19 pandemic, there was not a suitable return address for paper surveys to be returned to, and as such, this method of survey completion was not available. Participants requesting this method of survey completion were informed of this and were directed to the online version of the survey. It is acknowledged that this may have limited the number of people able to participate in the study. Participants who completed the survey were forwarded to a de-brief form (Appendix G) and given a choice to be entered into a prize draw to win a £50 Amazon voucher.

Materials

Demographics

Data pertaining to the participant's age, sex, relationship status, the specific diagnosis of the PwD, length of time spent in the caregiving role, own physical health, and the source of recruitment were collected (Appendix H). The Self Compassion Scale-Short Form, Compassionate Engagement and Action Scales, and support usage questionnaire appeared at the beginning of the survey. All other scales were randomised once uploaded to Qualtrics.

Primary outcome measures

Self-compassion. Self-compassion was assessed using the Self-Compassion Scale-Short Form (SCS-SF; Raes, Pommier & Gucht, 2011; Appendix I). The SCS-SF consists of 12 items in which participants rate their response on a Likert scale from 1 (almost never) to 5 (almost always). The SCS-SF measures three domains of self-compassion: self-kindness versus self-judgement, common humanity versus isolation, and mindfulness versus over-Identification. Higher scores indicate a high level of self-compassion. The SCS-SF has been found to have high internal consistency ($\alpha = .86$; Raes, Pommier & Gucht, 2011). The SCS-SF has also demonstrated a strong correlation with the longer form of the self-compassion scale (Raes, Pommier & Gucht, 2011), and as such, was selected to reduce the time commitment required of participants when completing the questionnaires.

Flows of compassion. The compassionate engagement and action scales (CEAS; Gilbert et al., 2017; Appendix J) were used to assess participant's levels of compassion in its three flows (self-self, other-self, self-other). The CEAS consists of three self-report subscales, each containing 12 items which are rated using a 10-point Likert scale with high scores indicating higher levels of compassion. Internal consistency for each of the CEAS subscales was found to range from $\alpha = .72 - .91$ (Gilbert et al., 2017).

Use of support. Participants were asked to retrospectively rate their support usage (both informal and informal) using bespoke questions detailing the amount and type of support utilised over the last month (Appendix K).

Caregiver burden. The Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson,1980; Appendix L) was used to capture caregiver burden. The ZBI consists of 22 items in which participants record how frequently they experience issues specific to caregiver burden on a 5-point Likert-type scale where zero = never and four = nearly always. Scores above 17 are considered to indicate high levels of burden (Bédard et al., 2001). The ZBI has been found to have high internal consistency with an α = .88- .92 (Harkness & Tranmer, 2007).

Attachment style. The Experience of Close Relationships- Short form (ECR-SF; Wei et al., 2007; A copy can be found in Appendix M). ECR-SF consists of 12-items (α's = .77 to .87) aiming to capture the attachment styles of adult respondents. The ECR-SF contains two subscales, each assessing different attachment styles (avoidant and anxious). High scores on each of the subscales are suggestive of the presence of either anxious or avoidance attachment styles. The psychometric properties of the ECR-SF were found to be comparable with the original ECR, including internal consistency, test-retest reliability, factor structure, and validity (Wei et al., 2007). As such, the short-form version of the ECR was selected to reduce the length of time participants are required to spend completing the questionnaire.

Qualitative measures

Alongside the quantitative data generated from the survey, qualitative data was also collected through free-text questions embedded into the survey. These questions explored their decisions to access support and the extent to which participants experienced the support offered to them as being compassionate (Appendix N).

Analysis

Quantitative data

Statistical Package for the Social Sciences (SPSS, Version 27; IMB corp, 2020) was used to conduct data analyses. The planned analyses were originally hierarchical linear regression; however, due to the impact of the COVID 19 pandemic on the recruitment of participants, an alternative method of analysis was selected to account for the small sample size and homogeneity in the sample. As such, a multinomial logistic regression was deemed to be more appropriate to examine whether the independent variables predicted membership to groups based on the level of support use. To permit these analyses and improve statistical power, data pertaining to the use of support were re-coded into categories, low (0-1), medium (2-3), and high (3-4). Descriptive analysis of survey data and participant demographics was completed using measures of central tendency (means, standard deviations or proportions). Means plots were then used to examine patterns in the means of each group. Next, one-way analysis of variance (ANOVA) were conducted to examine whether there were any statistically significant differences between the support use groups. Following this, a multinomial logistic regression (MLR) was then conducted to examine the extent to which the independent variables (self-compassion, compassion from others, attachment style, or perceived burden) predicted levels of support usage (low, medium, high).

MLR is an effective method of testing hypotheses regarding the relationship between categorical dependant variables and continuous predictor variables (Peng & Nichols, 2003). It was selected as the analysis method of choice in the present study due to its ability to provide an estimated probability of group membership (e.g., level of support use; Peng, Lee, & Ingersoll, 2002) along with an estimation of the net effects of the predictor variables (self-compassion, other-to-self compassion, attachment style, and burden). Sample size guidelines for multinomial logistic regression indicate a minimum of 10 cases per predictor variable

(Schwab, 2002; cited in Starkweather & Moske, 2011). Therefore, with five independent variables of interest (self-compassion, other-to-self compassion, attachment style [anxious and avoidant], perceived burden), a total sample size of 50 participants was required to permit analyses. Additionally, adequate minimum sample sizes for exploratory or pilot studies have been suggested to be 24-50 participants (Julius, 2005; Hooper, 2014). Consequently, a minimum sample size of 50 was deemed to be acceptable.

Qualitative data

Analysis of the qualitative data was conducted using template analysis. As is common in template analysis, *a priori* themes were used to limit the focus of the analysis to the research question (Brooks et al., 2015). This method of analysis was chosen to accelerate the coding phase of the qualitative analysis and to ensure comparability and applicability to the research question in conjunction with the quantitative data. *A priori* themes were developed based on the 'flows' of compassion (self-self, self-other, other-self). However, if the pre-set themes were found to be ineffective in capturing the data, new themes were developed iteratively during analysis. As such, the process of analysis was completed in six stages (King, 2012):

1. **Familiarisation with the data:** Data from the open-ended questions from the survey were merged, read, and re-read by the lead researcher.

2. **Preliminary coding:** The *a priori* themes were applied to a subset of data as tentative codes. These were adapted or removed based on their applicability to the data, and new themes emerged if the a priori themes prove to be ineffective.

3. **Clustering of themes:** A selection of themes were then sorted into meaningful clusters.

4. **Define coding template:** The clusters/themes were used to define an initial coding template for application to the remaining un-coded data.

5. **Application of template:** At this stage, the template was adjusted or modified based on its applicability to the new data.

6. **Finalisation of template:** The modified template was then applied to all of the data; the process of adjusting the template ceased once all data pertaining to the research question had been adequately coded.

Data were cross-checked and audited by a peer also engaging in qualitative research using an auditing template (Appendix O). Previous versions of the template were preserved as a means of providing an audit trail of decisions made during interpretation (Appendix P).

Merging and Triangulation of data

Following the analysis of both data types, the data were merged through a process of triangulation. The process of triangulation was informed by the triangulation protocol set by Farmer et al. (2006) and involved six steps:

1. **Sorting:** Findings related to the research question from both data sets were sorted and separated from the data. Key themes were then extracted and used to form the rows of the convergence coding matrix.

2. **Convergence coding:** The findings of both data sets were then compared using defined comparison elements (e.g., frequency of theme, specific examples) to the previously identified themes to examine convergence. The type of convergence will then be categorised and recorded. Types of convergence to be included are:

   a. Agreement: full agreement between both sets of findings on all aspects of comparison.

   b. Partial agreement: there is agreement between the data sets on some, but not all elements of comparison.

   c. Silence: the theme is covered by one data set but not the other

d. Dissonance: there is divergence between the data sets on the given element of comparison.

3. **Convergence assessment:** The convergence codes for all themes were reviewed to provide an overall assessment of convergence. Any disagreements between researchers regarding convergence codes were documented.

4. **Completeness assessment:** The scope of coverage for each theme were then reviewed and any themes with discrepant levels of coverage were identified.

5. **Researcher comparison:** The convergence and completeness assessments were then compared by both researchers to clarify interpretations. Any disagreements were discussed until an agreement was reached.

6. **Feedback:** Finally, the triangulated results were reviewed and clarified.

Service User involvement

Caregivers who attended a caregiver support group provided by a charity in the north of England were consulted during the design of this project. During the development stage of the project, the priority of the research aims, methods of recruitment, and choice of outcome measures were developed in consultation with group members. Although ongoing consultation was intended, this was impacted restrictions caused by the COVID-19 pandemic and was therefore not deemed to be practical. However, once the present study has been submitted for publication, participants will be informed through an article in the charity's newsletter.

Results

Quantitative data

Overall, 41% of participants rated the support offered to them as 'very compassionate', 29% 'quite compassionate', 8% 'somewhat compassionate', 2% 'not at all

compassionate', and 18% declined to answer. Descriptive statistics relating to the predictor variables (self-compassion, other-to-self compassion, attachment style, burden) by each level of support use (low, medium, high) can be found in Table 3.

Firstly, mean plots were constructed with the aim of visually examining any differences in the means of each group (see Appendix Q). Visual analysis of the means plots indicated a small positive trend for self-compassion (SCS-SF, CEAS-Self) and burden between the groups, with those in the low support group scoring lower on self-compassion than those in the medium and high support groups. The mean plot for compassion from others also indicated an increase in scores for those in the high support group relative to the low and medium support groups. The mean plot for avoidant attachment styles demonstrated a slight negative trend, with those in the low and medium support groups scoring higher than those in the high support group. Finally, the mean plot for anxious attachment demonstrated a 'V' shaped pattern, whereby those in the low and high support groups appeared to score high on this measure compared to those in the medium support group.

One-way analysis of variance

There were no statistically significant differences between any of the groups for any of the independent variables (Table 4). Post-hoc tests using the Bonferroni correction confirmed this finding and did not indicate that there were any statistically significant differences in the independent variables between the three levels of support use groups. Post-hoc tests using Bonferroni corrections were utilised due to their propensity for use with small sample sizes (Field, 2009).

Table 3

Summary of descriptive statistics by support use group

Measure	Whole sample (N=51)	'low' support use (N=24)	'medium' support use (N=15)	'high' support use (N=12)
	M (SD)	M (SD)	M (SD)	M (SD)
SCS-SF	3.36 (.89)	3.27 (.82)	3.39 (.82)	3.53 (.79)
CEAS				
Self-compassion	66.86 (15.65)	62.71 (15)	70 (15.56)	71.25 (17.23)
Compassion to others	82.48 (11.30)	80.50 (11.53)	85.93 (10.87)	82.08 (11.27)
Compassion from others	60.96 (20.38)	58.50 (25.80)	58.73 (25.80)	68.67 (14.61)
ZBI	40.94 (14.36)	38.64 (13.94)	41.47 (13.44)	44.92 (16.50)
ECR				
Avoidant	18.92 (8.52)	20.04 (7.13)	20.27 (10.75)	15 (7.40)
Anxious	16.12 (6.65)	16.79 (5.45)	14.53 (8.45)	16.75 (6.55)

Note. SCS-SF: Self-compassion scale; CEAS: Compassionate engagement and action scales; ZBI: Zarit burden inventory; ECR: Experience of close relationships.

Table 4

One-way analysis of variance (ANOVA) between the groups and level of support use

Measure	Source of variance	SS	df	MS	F	p-value
SCS-SF	Between groups	0.55	2	0.27	0.33	.72
	Within groups	39.19	48	0.82		
	Total	39.74	50			
CEAS						
Self-compassion	Between groups	792.83	2	396.42	1.66	.20
	Within groups	11453.21	48	238.61		
	Total	12246.04	50			
Compassion to others	Between groups	274.86	2	137.43	1.08	.35
	Within groups	6105.85	48	127.21		
	Total	6380.71	50			
Compassion from others	Between groups	932.32	2	466.16	1.13	.33
	Within groups	19837.60	48	413.28		
	Total	20769.92	50			
ZBI	Between groups	322.55	2	161.27	0.78	.47
	Within groups	9994.28	48	208.21		
	Total	10316.82	50			
ECR						

Avoidant	Between groups	241.80	2	120.90	1.71	.19
	Within groups	3387.89	48	70.58		
	Total	3629.69	50			
Anxious	Between groups	53.35	2	26.68	0.59	.56
	Within groups	2155.94	48	44.92		
	Total	2209.29	50			

Note. SCS-SF: Self-compassion scale; CEAS: Compassionate engagement and action scales; ZBI: Zarit burden inventory; ECR: Experience of close relationships.

Multinomial Regression

The multinomial regression revealed that none of the independent variables acted as significant predictors for level of support use as defined by the three groups (low, medium, high). Table 5 contains the model fitting information which indicates the extent to which the model accounts for the data. As this is non-significant, it indicates that the model does not represent an improvement in fit over the null model and as such, does not significantly account for the data.

Table 5

Model fitting information

Model	2 Log Likelihood	Chi-square	df	Sig.
Intercept only	107.62			
Final	95.36	12.26	10	.27

The contribution for each of the predictor variables to the model can be found in Table 6. This demonstrates that none of the predictor variables contributed significantly to the model

Table 6

Likelihood Ratio Tests

Effect	Model fitting criteria	Likelihood ratio tests		
	-2 Log likelihood of reduced model	Chi-square	df	Sig
Intercept CEAS	98.12	2.76	2	.25
Self-compassion	97.45	2.09	2	.35

Compassion from others	96.60	1.24	2	.54
ZBI	98.51	3.15	2	.21
ECR				
Avoidant	96.33	0.97	2	.62
Anxious	96.29	0.93	2	.63

Note. SCS-SF: Self-compassion scale; CEAS: Compassionate engagement and action scales;

ZBI: Zarit burden inventory; ECR: Experience of close relationships.

The extent to which each predictor variable is able to discriminate against those in the medium and high support use groups relative to the low usage group is shown in Table 7. Again, none of the predictor variables were able to significantly discriminate between those in the medium or high support use groups relative to the low support use group. Similarly, the odds of membership to the medium or high support use groups relative to the low usage groups range from OR=0.95 to OR=1.08, suggesting that the independent variables do not impact the odds of membership to either support use group.

Although non-significant, there was a small change in the level of non-significance in the compassion from others variable, with the *B* in the low and medium groups being almost identical (*B*= -.00*)* but slightly more significant in the high group (*B*= .03). There was also a change in the direction of the coefficient for the two measures of attachment style with a negative non-significant relationship observed for anxious attachment in the high group, and a positive non-significant relationship observed in the medium group with the low group acting as the reference for both. Conversely, a positive non-significant relationship was observed for avoidant attachment in the medium group, and a negative non-significant relationship was observed for the high group.

Table 7

Parameter Estimates

Group	Variable	*B*	*SE*	Wald	df	Sig.	Exp(B)	95% CI for Exp(B) Lower	Upper
Medium	Intercept	-4.66	4.41	1.12	1	.29			
	CEAS								
	Self-compassion	.04	.04	1.59	1	.21	1.04	.976	1.12
	Compassion from others	-.00	.02	.00	1	.96	.999	.954	1.05
	ZBI	.03	.03	1.00	1	.32	1.03	.97	1.09
	ECR								
	Avoidant	.02	.06	.52	1	.47	1.02	.92	1.14
	Anxious	-0.2	.08	.62	1	.43	.99	.85	1.14
High	Intercept	-7.92	5.34	2.20	1	.14			
	CEAS								
	Self-compassion	.04	.04	1.10	1	.29	1.04	.96	1.13
	Compassion from others	.03	.03	1.01	1	.32	1.03	.97	1.09
	ZBI	.05	.03	2.78	1	.10	1.06	.99	1.12
	ECR								
	Avoidant	-.05	.07	.52	1	.47	.95	.83	1.01
	Anxious	.07	.09	.62	1	.43	1.08	.90	1.30

Note. SCS-SF: Self-compassion scale; CEAS: Compassionate engagement and action scales;

ZBI: Zarit burden inventory; ECR: Experience of close relationships.

Qualitative Findings

The three *a priori* themes of self-compassion, self-to-other compassion and other-to-self compassion were applied to the data as first-level themes. The themes of self-compassion and other-to-self compassion were found to be appropriately applicable to the data. As the majority of the data focussed on the experiences of caregivers receiving support, rather than providing support, the theme of self-to-other compassion was not found to be appropriate and was consequently discarded. A total of seven second-level themes also emerged from the data during the process of analysis. Of these, the theme of other-to-self compassion accounted for the largest proportion of the data. Figure 1 depicts the final coding template. All first and second-level themes are described below along with extracts from case examples.

Figure 1

Final coding template

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1. **Self-compassion**

   a. *Knowing what is and is not helpful*

   b. *Caregiving role as a barrier*

2. **Other-self compassion**

   a. *Intrusive and antagonising*

   b. *Inappropriate support*

   c. *Inaccessible services*

   d. *Support being distressing for the recipient of care*

   e. *Risks of COVID-19*

Self-compassion

This theme reflected participant's ability to act compassionately towards themselves through attending to their needs and focusing on what was beneficial for them. A total of five participants contributed to this theme.

Participants frequently reported being offered support that did not fit their needs, and some stated that they had decided against using support offered to them due to concerns about the impact it may have on them. This was interpreted as representing an ability to be sensitive to one's own needs and acting accordingly, which is indicative of self-compassion.

"Mixing with older age care givers, not helpful for me."- P24

Other participants reported feeling they do they not require support at the present time whilst acknowledging that their needs may change in the future.

"At the moment, I feel like I am capable of looking after my husband"-P45

Another participant reflected that the time commitment of their caregiving role acting as a barrier to them accessing support.

"It [the support] was quite compassionate…I just don't feel I have the capacity to get involved in anything else currently as feel my caring responsibilities take up so much time"-P46

Compassion from others

This theme explored participant's experiences of being offered support and the extent to which they perceived this as being compassionate. It is worth noting that the vast majority of participants rated the support offered to them as being compassionate. However, those who did not view the support offered to them as being compassionate provided more qualitative description of why they felt this way. This was the largest of the two first-level themes, with a total of thirteen participants contributing to this theme.

Participants spoke of feeling like others asking questions about their caregiving role sometimes felt intrusive and antagonistic, whether it be from formal services such as mental health teams or social care or by family members or neighbours.

"Social Services assessment was intrusive, antagonistic and misleading"- P47

This seemed particularly prevalent when participants felt like they were not being listened to by the individual offering support.

"wanted to know too much personal information instead of just listening"- P48

The provision of inappropriate support was also experienced by participants as being less compassionate than support that was offered based on their individual needs. Participants

spoke of being impractical or unnecessary support which made them feel like they were not being listened to.

"It was offered without really understanding our needs or asking us what we wanted." -P20

Health and Social Care services were also seen as being inaccessible by some of the participants, with some finding that they had to work hard to assert their needs and get the support they require.

"The local mental health team make it seem like they have a box to tick by visiting once a year, and once that box is ticked they're hard to reach out to" -P22

Some participants also reported experiencing these barriers to support as being a reflection of them as a caregiver and the perceptions of others of them being unreasonable or invisible.

"[they] made me feel I was being unreasonable."- P34

This theme also reflected participant's experiences of considering the support offered to them in the context of those they cared for. This tended to centre around the support being inappropriate for the PwD and in one case, support was offered at a time of the day that causes additional confusion for the PwD.

"We were offered carer visits at 7 in the morning which was too early to be of any benefit and would have resulted in mum being more confused" -P44

Caregivers reported declining any support that may distress their loved ones. This demonstrated a prioritisation of the needs of the person receiving support and a process of

considering not only their perceptions of compassion from others towards themselves but also the compassion from others towards the PwD.

"Online or telephone support is impractical because my husband interrupts or listens in" -P26

Additional considerations as a result of the COVID 19 pandemic also impacted the likelihood of participants accepting support offered to them. For example, concerns regarding allowing others into their home and the potential risk of infection. As such, participants reported declining support that may involve increased risk to their loved ones.

"Risk of carers bringing covid into the home where I am shielding my mum"- P34

Triangulation

The process of triangulation revealed that there are areas of both convergence and divergence in the findings. A clear area of full convergence is that both the quantitative and qualitative aspects of the study generated only small amounts of data. In terms of partial agreement, the high level of self-compassion captured on the quantitative measures were deemed to partially reflect the caregiver's accounts of self-compassion as being an important factor in the decision to access support. Responses such as "*mixing with older age caregivers, not helpful for me*" demonstrate an ability to reflect and act on one's own needs, which is in keeping with the generally high scores on the measures of self-compassion. Furthermore, although there were no statistically significant differences between mean self-compassion for each support use group, there was a categorical difference between the mean self-compassion scores for those in the low-medium support use groups (low support = 3.27, 'moderate'; medium support = 3.39, 'moderate') in comparison to the high support use group (3.53, 'high').

Similarly, the quantitative scores of burden indicate the presence of a high mean level of burden across all participants (40.94). This is in partial agreement with the qualitative findings, which found that some participants reported that accessing support was difficult due to the commitments of their caregiving role (e.g., "*I just don't feel I have the capacity to get involved in anything else*"). However, the level of burden was not found to be a statistically significant predictor of support use.

The complexity and importance of caregiver's experiences of receiving compassion from others when considering whether to access support was found only in the qualitative data and as such, as deemed as an area of dissonance. The quantitative data showed that there were no statistically significant differences between the mean scores on this measure for any of the support use groups, and that it was not a significant predictor of the level of support utilised by participants. However, the qualitative findings reflected that caregiver's perceptions of the compassion they receive from others, either towards themselves or those they care for, did have an impact on whether they chose to access the support. For example, this participant reported that they did not choose to access the support as "*it was offered without really understanding our needs or asking us what we wanted*". This suggests that the extent to which those offering support were perceived to be sensitive to their needs was factored into decisions in whether to access that support.

Discussion

To the author's knowledge, this study is the first to explore the role of compassion in decisions to access support by caregivers of PwD. Contrary to the hypotheses, the study found no statistical evidence for a relationship between self-compassion, other-to-self-compassion, burden, attachment style, and level of support use in caregivers of PwD. However, qualitative data suggests that for some caregivers, the extent to which those

offering support were seen as being compassionate did impact upon their decisions whether to access the support offered to them.

In contrast to the existing literature, this study found no statistical evidence that level of burden was associated with support use. This may have been due to the surprisingly high overall level of burden that was observed across all the support use groups. As previously stated, a score of >17 on the ZBI is considered to be indicative of high levels of burden, with the mean burden score for participants in the present study being 40.94. This is particularly pertinent, as burden has previously been found to be negatively associated with self-compassion (Lloyd et al., 2018). This again is in contrast with the findings of the present study, which found that participants scored highly on both burden and self-compassion.

There is evidence to suggest that caregiver populations, particularly those caring for PwD, have been disproportionately impacted by the COVID 19 pandemic and resulting restrictions (Altieri & Santangelo, 2021; Boutoleau-Bretonnière et al., 2020). Research with other caregiving populations has suggested that the COVID 19 pandemic has resulted in an increased level of perceived burden, increased negative symptomatology and higher levels of perceived stress in those they are caring for (Russel et al., 2020). As such, the high level of burden observed in this study may be indicative of the increased pressures due to the impact of the pandemic, which may have obscured potential relationships. Nevertheless, these findings do support previous research that suggests that PwD generally experience high levels of burden as part of their caregiving role and further highlights the importance of developing our understanding of how to best support this population.

In terms of the role of compassion, although there were trends in the data suggesting that support increased in those scoring higher on the self-compassion and other-to-self compassion subscales, this was not found to be statistically significant. Qualitative data

collected from a small proportion of the participants did, however suggest that self-compassion and other-to-self compassion may impact their decisions to access support. As such, further qualitative research may be beneficial in developing our understanding of the role of other-to-self compassion for caregivers of PwD, particularly for those who report experiencing low levels of support use. Similarly, some participants reported that their caregiving role was a barrier to them acting compassionately towards themselves. This suggests the need for future research examining the effectiveness of self-compassion as an intervention target (Murfield, Moyle & O'Donovan, 2019).

However, it is worth noting that there was generally little variation in participant's scores on the self-compassion subscales, with the majority of participants scoring highly on these measures. It is not clear whether this is reflective of the wider population of caregivers of PwD. Future research aimed at examining the baseline levels of self-compassion in this population may be beneficial in providing further support for the usefulness of compassion-based interventions in this population.

Strengths and limitations

The findings of the present study should be interpreted in the context of its strengths and limitations. A particular limitation of the study is the small sample size, which may have impacted the findings in several ways. Firstly, as recruitment failed to achieve the number of participants required to achieve statistical power, the study was underpowered, which may have increased the likelihood of type II errors (Kaur & Stoltzfus, 2017). This may either mean that the lack of significant results is indicative of the null hypothesis being correct or that the study was insufficiently powered to detect any relationships that are in fact present. Attempts to increase the statistical power of the study were made, such as the adaptation of the methods of analysis to reflect the small sample size. However, the lack of power may still

provide some explanation for the discrepancies between the qualitative and quantitative aspects of the study, for example, the extent to which themes such as other-to-self compassion were seen as having an impact on decision making. As such, the results should be interpreted cautiously.

Secondly, although all participants had the option of completing the open-ended questions, only 17 participants completed this section of the survey. This may have meant that there was a bias in the qualitative data, as it may have been that only the experiences of those who had negative experiences of support were captured. This is in keeping with existing research, which suggests that those with negative experiences are far more likely to respond to open-ended questions (e.g. Reynolds, McKernan & Sukalski, 2020). As such, the voices of those who have experienced greater levels of compassion in the support offered to them may have been missed.

A further limitation of the study is due to the homogeneity in the sample. For example, participants were overwhelmingly white, female and most were over the age of 55. Participants in this study also scored similarly highly on measures of compassion, burden, and attachment style, which meant there was a distinct lack of variance in the data. This may have been due to the over-reliance on particular avenues for recruitment; for example, participants were recruited using online platforms, predominantly in forums for caregivers interested in participating in research. This may have meant that their motivations for participating in the research were similar, which could have introduced a source of bias. Furthermore, it meant that caregivers who were less computer literate or who were more isolated in their caregiving role may not have been able to participate and were not represented.

Despite these limitations, this study is the first to employ mixed-methods methodology to explore the role of compassion in the use of support by caregivers of PwD. The use of both qualitative and quantitative methods to explore this concept is advantageous in allowing for both the richness of individual experience as captured by qualitative data and the generalisability of quantitative data. A common pitfall of mixed-methods research is the failure to adequately plan and complete a synthesis of the data types (Gibson, 2017). As such, a strength of this study is its conformity to standardised guidelines for the triangulation of mixed-methods data.

A further strength of this study is the presence of a range of dementia diagnoses in the caregiver groups, including rarer sub-types such as posterior cortical atrophy and young-onset dementia. Although Alzheimer's and Vascular dementia were the most common diagnoses of the individuals receiving care, this is reflective of the general population as those dementia subtypes are more prevalent (Brunnström et al., 2009). The inclusion of a range of dementia sub-types that are reflective of the general population increases the generalisability and external validity of the findings.

Future Directions

As mentioned previously, white female participants over the age of 55 were over-represented in the present study. This is also reflective of the larger evidence base of research into caregivers of PwD and greater diversity has a been raised as a priority for future research (Houde, 2002). Consequently, far less is known about the caregiving experience for other populations such as those identifying as genders other than female, younger adult caregivers, and those from other cultural backgrounds. Future research exploring the caregiving role in underrepresented populations would therefore be prudent.

Research into the role of compassion in its three flows is in its infancy, and measures designed to capture this concept, such as the CEAS, have only recently been validated for use in older adult populations (Murfield, Moyle & O'Donovan, 2019). As such, future research applying measures of compassion such as the CEAS would be advantageous in furthering understanding of these distinct aspects of compassion in various caregiver populations. Similarly, future research utilising qualitative methodology is recommended in order to further explore the experiences of caregivers of PwD, particularly regarding their experiences of other-to-self compassion.

Clinical Implications

The findings of the present study highlight the importance of providing compassionate and tailored care for caregivers of PwD. Many of the qualitative themes that emerged centered around the experiences of participants of receiving offers of support that were not perceived as being compassionate nor sensitive to their needs. Compassion is central to the delivery of good quality care; however, the way it is conceptualised by health professionals can vary (Bray et al., 2014) and is often impacted by limitations in time and resources (Dewing & Dijk, 2016).

Unfortunately, the experience of overly task-orientated or non-compassionate care for PwD and their caregivers is common (Bickford et al., 2019), which has led to an increased focus on increasing understanding of how to implement compassionate care in a meaningful way for caregivers of PwD (Blagg & Petty, 2015). Although tentative, the findings of this study suggest that caregivers value tailored support and view this as being more compassionate than more generalised offers of support that do not take their specific needs into account. As such, services should strive to ensure that they are sensitive and flexible to the needs of both the individual with dementia and their caregiver.

As previously mentioned, the qualitative data also tentatively suggests a potential role for self-compassion interventions, as advocated by previous research (Murfield, Moyle & O'Donovan, 2019). This might be particularly pertinent for caregivers who do not report experiencing high levels of self-compassion, which suggests that an assessment of compassion may have utility in identifying those who may benefit from intervention.

Conclusions

In conclusion, this study provides an exploration of the role of compassion in the experiences of caregivers of people with dementia who are making decisions regarding accessing support. The results demonstrate that self-compassion and other-to-self compassion was not associated with the level of support use; however, qualitative findings suggest that other-to-self compassion did influence whether individuals chose to access support. Triangulation revealed that there were common themes across the data sets with generally high levels of self-compassion, other-to-self compassion, and burden being present. These findings, although tentative, may advocate the need for the provision of compassionate, tailored support for caregivers of PwD. Future research further exploring the role of compassion in this population would be beneficial, particularly for underrepresented populations and caregivers who are more isolated in their caregiving role.

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Appendices

Appendix A   Ethical Approval Form

Appendix B   Example email to charities

Appendix C   Study Advertisement for social media

Appendix D   INVOLVE Summary for Join Dementia Research

Appendix E   Participant Information Sheet

Appendix F   Consent form

Appendix G   Debrief Form

Appendix H   Demographics form

Appendix I   Short Self-compassion Scale (Raes et al, 2011) REDACTED

Appendix J   Compassionate Engagement and Action Scales (Gilbert et. al., 2017)

REDACTED

Appendix K   Support usage

Appendix L   Zarit Burden Interview (Zarit, Reever, & Bach-Peterson,1980)

REDACTED

Appendix M   Experiences of Close Relationship- 12 Item (Wei et. at., 2007)

REDACTED

Appendix N   Open-ended questions

Appendix O   Peer audit form for template analysis

Appendix P   Previous versions of coding template

Appendix Q   Mean plots

Appendix A: Ethical Approval Form

Poppy Siddell
Registration number: 180156911
Psychology
Programme: Doctorate in Clinical Psychology

Dear Poppy

PROJECT TITLE: Compassion and the use of support by family caregivers of people with dementia: An exploratory mixed methods study
APPLICATION: Reference Number 032247

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 29/03/2020 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 032247 (form submission date: 25/03/2020); (expected project end date: 12/05/2021).
- Participant information sheet 1073974 version 1 (17/12/2019).
- Participant consent form 1073975 version 1 (17/12/2019).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Thomas Webb
Ethics Administrator
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:
  https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy:
  https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Amendments to ethical approval.

1. Amendment to recruitment- addition of social media

2. Amendment to recruitment- addition of Join Dementia Research

Appendix B: Example email to charities

Example email for contacting charities

Hi [insert name]

My name is Poppy Siddell and I am a trainee clinical psychologist at the University of Sheffield. I am currently recruiting participants for a research project that I am completing as part of my university course. I am getting in contact with you to see whether it would be possible for me to share the details of the project with your members.

The project aims to explore how individual differences may influence the use of support by caregivers of someone with dementia. The study will take approximately 20 minutes to complete and can be done either online or on paper. All participants who take part in the study will be given the option to enter a prize draw to win a £50 Amazon voucher.

The study has undergone appropriate ethical review. Please see attached my ethical approval letter, advertisement and information sheet for participants.

If you have any questions, and/or would like to talk me to me about the project in more detail, you can contact me either by email (psiddell1@sheffield.ac.uk) or over the telephone on 07917662351.

I appreciate your time in reading this email and I look forward to hearing from you.

Kind regards,

Poppy Siddell
Trainee Clinical Psychologist

Supervised by: Dr Fuschia Sirois
Department of Psychology

Appendix C: Study Advertisement for social media

Are you supporting someone with a diagnosis of dementia?

We invite you to participate in a study about how individual difference might influence the use of support by caregivers of someone with dementia. Anyone currently providing support for someone with dementia is eligible to participate.

The study is completed online and your data will anonymised. The study will take approximately 20-30 minutes to complete, although individual completion times may vary. All participants who take part in the study will be given the option to enter a prize draw to win a £50 Amazon voucher.

For more information and/or to participate please click here.
https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_9uWzJxOP5YLwyhf

This questionnaire has received ethical approval from the Department of Psychology Ethics Committee at the University of Sheffield.

Please feel free to pass this message on to anyone who may be interested!

Many thanks,

Poppy Siddell, trainee clinical psychologist
Dr. Fuschia Sirois, supervisor
Department of Psychology
University of Sheffield

Appendix D: INVOLVE Summary for Join Dementia Research

Title: An online study to measure individual differences and the use of support by caregivers

Please note: This is an online study; you will not be contacted by a researcher. If you want to take part in this research study, please click on the following link:
https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_9uWzJxOP5YLwyhf

Background:
Caring for someone with dementia can be challenging and can have a significant impact on wellbeing. Services exist to help and support carers but people might make different choices about whether to access these services or not. This study is interested in how individual differences might influence people's decisions to access services.

Aims of research study:
Questionnaire study to look at the role of individual differences in the use of support by people who care for someone with dementia.
This study has been designed with the help of members of a support group for carer's of people with dementia. This involvement helped to shape the development of the research project.

Volunteers:
Full or part time unpaid carer
Over 18 years of age
Must be looking after someone with a diagnosis of dementia

What does the study involve?
Online questionnaire that will take around 30 minutes to complete. If you would like to take part in this study you can access it here:

https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_9uWzJxOP5YLwyhf

Participant Information Sheet

Individual differences and the use of support by caregivers of someone with dementia

Researchers

Lead Researcher: Poppy Siddell psiddell1@Sheffield.ac.uk

Supervised by: Dr Fuschia Sirois f.sirois@sheffield.ac.uk

Study Information

You are being invited to participate in this research project. This information sheet explains why the research is being done and what it will involve, to help you decide whether you would like to take part. Please take the time to read the following information carefully.

Why have I been chosen?

We are contacting people who are providing care for a friend or family member with dementia.

What is the study about?

We are looking at the role of individual differences in the use of support by people who care for someone with a diagnosis of dementia.

What will taking part involve?

The study involves completion of an online questionnaire which looks at individual differences and the frequency of support use. Use of support relates to both formal (e.g. NHS services, charities) or informal (e.g. from friends/ family) support used. The questions may also ask you to reflect on the support you have used during the COVID-19 pandemic.

This will take about 20 minutes to complete. Upon completion, you will entered into a prize draw to win a £50 Amazon voucher.

Are there any disadvantages or risks of taking part?

Some of the questions may lead you to reflect on your role as a caregiver and your access to support which may be distressing. If this does happen, you can choose to complete the survey later or withdraw from the study altogether. If taking part in this study does raise awareness of any difficulties you may be having, then you may find it helpful to speak to your GP about the support available to you.

Are there any benefits in taking part?

Reflecting on your role as a caregiver and use of support may have some benefits; however, this is not the intention of the current study. Instead, we hope that the results will add to the research in the area and be used to inform the development of services for caregivers.

Who is organising and funding the study?

The University of Sheffield is organising this study.

Who has ethically approved this study?

This study has been ethically approved by the University of Sheffield's Psychology Research Ethics Committee.

Legal statement under the General Data Protection Regulation (GDPR)

New data protection legislation comes into effect across the EU, including the UK on 25 May 2019; this means that we need to provide you with some further information relating to how your personal information will be used and managed within this research project. This is in addition to the details provided within the information sheet that has already been given to you. The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'.

Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice:

https://www.sheffield.ac.uk/govern/data-protection/privacy/general .

What will be done with the data and results?

If you wish to be entered into the prize draw, will be asked to provide your email address, and if you are successful, we will use it to contact you. All data will be anonymized and held securely.

The results from this study will be written up and submitted as a thesis for the clinical psychology doctorate at the University of Sheffield. Additionally, the results will be disseminated through publishing in a peer-reviewed journal. No participants will be identifiable in any publications as data will be pooled from all participants.

What if I wish to complain about the way the study has been carried out?

If you would like to make a complaint about this project, in the first instance you should contact the lead researcher (Poppy Siddell). If you do not feel satisfied that your complaint has been dealt with appropriately you can contact the lead researcher's supervisor. If you feel that your complaint has not been handled to your satisfaction following this, you can contact. Prof Glenn Waller, Head of Department at g.waller@sheffield.ac.uk

What next?

If you have any questions or would like a paper copy of this information please email psiddell1@sheffield.ac.uk. If you would like to take part, then please click the link provided to consent to the study and then complete the questionnaires. As previously stated, you can withdraw at any time.

Individual differences and the use of support by caregivers of someone with dementia
Consent Form

Please tick the appropriate boxes	Yes	No
Taking Part in the Project		
I have read and understood the project information sheet dated DD/MM/YYYY or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	☐	☐
I have been given the opportunity to ask questions about the project.	☐	☐
I agree to take part in this project. I understand that taking part in the project will include completing a questionnaire.	☐	☐
I understand that my taking part is voluntary and that I can withdraw from the study at any time prior to the submission of the survey. I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	☐	☐
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	☐	☐
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	☐	☐
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	☐	☐

Name of participant [printed]   Signature   Date

Name of Researcher [printed]   Signature   Date

Project contact details for further information:

Lead Researcher: Poppy Siddell psiddell1@Sheffield.ac.uk
Supervised by: Dr Fuschia Sirois f.sirois@sheffield.ac.uk
University address: Clinical Psychology Unit, University of Sheffield, Cathedral Court, Floor F, 1 Vicar Lane, Sheffield, S1 1HD
In the event of a complaint, please contact the head of department: Prof Glenn Waller
g.waller@sheffield.ac.uk

DEBRIEF FORM

Compassion and the use of support in caregivers of people with dementia

Supporting a loved one with dementia can be challenging and research has shown that providing care for a person with dementia can have an impact on the caregiver's wellbeing. One way to improve wellbeing is through the use of support, but often the use of support in caregivers of someone with dementia is low. The ability to identify one's own need for support and be motivated to resolve this is often related to the concept of compassion.

As such, the primary aim of this study is to explore how compassion may be linked to the use of support by those who provide care to people with dementia. In particular, we were interested in exploring how different elements of compassion (self-compassion, compassion from others and compassion to others) might influence the decisions of caregivers to access or accept support. An example of the elements of compassion can be found below:

The results from this research will be used to develop our knowledge in this area, and may be used to inform the provision of support services for caregivers of people with dementia in the future.

If taking part in this study has raised awareness of any difficulties you may be having, then you may find it helpful to speak to your GP about the support available to you.

Relevant resources and support:

Dementia UK: https://www.dementiauk.org/understanding-dementia/

Carers UK: https://www.carersuk.org

Alzheimer's association: https://www.alz.org

Thank you very much for your time - your thoughtful responses are greatly appreciated.

Sincerely,

Poppy Siddell

Trainee Clinical Psychologist

Supervised by Dr. Fuschia Sirois

Department of Psychology

University of Sheffield

If you have any further questions regarding the study please email the principle investigator, Poppy Siddell (psiddell1@sheffield.ac.uk).

Appendix H: Demographics form

Screening Questions:
Are you currently providing care for an individual who has a diagnosis of dementia?
YES_____   NO _____ (exit if selected)

Are you providing this care in a professional capacity? NO_____   YES _____ (exit if selected)

Do you identify as the main caregiver of the person with dementia? (defined as providing 5 or more hours of support per week)
YES_____NO _____(exit if selected)

General Information

Age: [____]   Sex: [__] Female   [__] Male   [__] Other

In what country/continent do you currently live?
- ❑ United Kingdom
- ❑ Europe
- ❑ Canada
- ❑ USA
- ❑ Australia
- ❑ South America
- ❑ Other (please list) _____

What ethnic/cultural background do you most identify with? (For example: White, Chinese, Latin American, Black, etc.)

_____

What is your relationship status? (please check the one that applies best to you)

	Married/Living with an intimate other		Never married
	Separated/Divorced		Widowed

How long have you been providing care for the individual with dementia?

What is their diagnosis? (e.g. Alzhiemer's, Vascular).

How would you best describe the support you provide for the person with dementia?

Social support ❑ Emotional support ❑ Support with personal cares (e.g. going to the toilet, washing/bathing) ❑ Practical support (e.g. helping with finances, helping with shopping) ❑ Other (please describe ❑…………

How do you rate your overall current health? (check one most appropriate box):
Excellent ❑ Very good ❑ Good ❑ Fair ❑ Poor ❑

Appendix I: Short Self-compassion Scale (SCS; Raes et al, 2011)

Appendix J: Compassionate Engagement and Action Scales (Gilbert et. al., 2017)

Appendix K: Support usage

Use of Support Questionnaire

Definitions:
- 'Compassion'- Being compassionate is defined as having "a sensitivity to suffering in self and others and a commitment to try to alleviate and prevent it."
- 'Support' is defined as anything that assists you in your caring role. The focus of this support can be varied and includes practical (e.g. finances), emotional (counselling, carers groups) or medical support (e.g. respite care). Support may be provided by family members, friends, community groups (e.g. church) or more formal services (e.g. NHS, memory services, respite, charities).

Have you made use of any form of support over since the beginning of lockdown?

☐ Yes

☐ No

☐ If **Yes**, what sort of support have you made use of?

☐ Friends (On average, how often have you made use of this support over the last month? …..)

☐ Family members (On average, how often have you made use of this support over the last month? …..)

☐ Religious/community groups (On average, how often have you made use of this support over the last month? …..)

☐ NHS services (On average, how often have you made use of this support over the last month? …..)

☐ Memory teams (On average, how often have you made use of this support over the last month? …..)

☐ Charities (Alzheimer's society, Carers UK) (On average, how often have you made use of this support over the last month? …..)

☐ Online support Communities (On average, how often have you made use of this support over the last month? …..)

☐ Other (if other, please specify ………) (On average, how often have you made use of this support over the last month? …..)

If **No**:

Since the beginning of lockdown, have you been offered support that you chose not to accept?

☐ Yes

☐ No

(Open-ended questions follow)

If **No**:

Were you making use of any support prior to lockdown?

☐ Yes
☐ No

If **Yes**, what sort of support have you made use of?

☐ Friends (On average, how often have you made use of this support over the last month? …..)

☐ Family members (On average, how often have you made use of this support over the last month? …..)

☐ Religious/community groups (On average, how often have you made use of this support over the last month? …..)

☐ NHS services (On average, how often have you made use of this support over the last month? …..)

☐ Memory teams (On average, how often have you made use of this support over the last month? …..)

☐ Charities (Alzheimer's society, Carers UK) (On average, how often have you made use of this support over the last month? …..)

☐ Online support Communities (On average, how often have you made use of this support over the last month? …..)

☐ Other (if other, please specify ………) (On average, how often have you made use of this support over the last month? …..)

If **No**:

Prior to the beginning of lockdown, have you been offered support that you chose not to accept?

☐ Yes
☐ No

(Open-ended questions follow)

Appendix L: Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980)

Appendix M: The Experiences of Close Relationship- 12 Item (Wei et. at., 2007)

Appendix N: Open-ended questions

These questions appeared to participants who answered both the prior to and during lockdown sections of the survey.

Please describe why you chose not to accept this support:
……
……
……
………………………………………………

To what extent, when people offered you support, did you see this as being compassionate? (Forced choice)

Not at all compassionate
Somewhat compassionate
Quite compassionate
Very compassionate

Was there a time (during lockdown/prior to lockdown) that you were offered support that you did not view as being compassionate? If **yes**, please describe:
……
……
……
…………………………………………….

What made you think that the support offered to you was not compassionate?
……
……
……
………………………………………………

Appendix O: Peer audit form for template analysis

Audit

Data collection
1. Is there evidence that raw data was collected and is appropriate for the research aims?

Yes (As evidenced by anonymised transcripts/photo-elicitation/data)
2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age)?

Yes
3. Are there reflections/notes/summaries on the data collection process?

Yes

Research/analysis process
4. Has the researcher engaged appropriately in supervision as part of the research process?

Yes
5. Has the data been sufficiently coded? (e.g. is all the relevant data coded?)

Yes
6. Has the data been systematically coded?

Yes

Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified?

Yes

Cross-checks
7. Crosschecking randomly selected excerpts from the survey responses

8. Are these consistent?

Yes
9. Vice-versa crosschecking randomly selected themes and subthemes against the corresponding data.

10. Are these consistent?

Yes

Study write-up/results
11. Are quotes sufficient to provide evidence of the themes and subthemes?

Yes
12. Does the results/write-up sufficiently address the aims of the study?

Yes

Signature of researcher

Signature of auditor

Appendix P: Previous versions of the coding templates

1. **Self-compassion**
    a. *Knowing what is and isn't helpful*
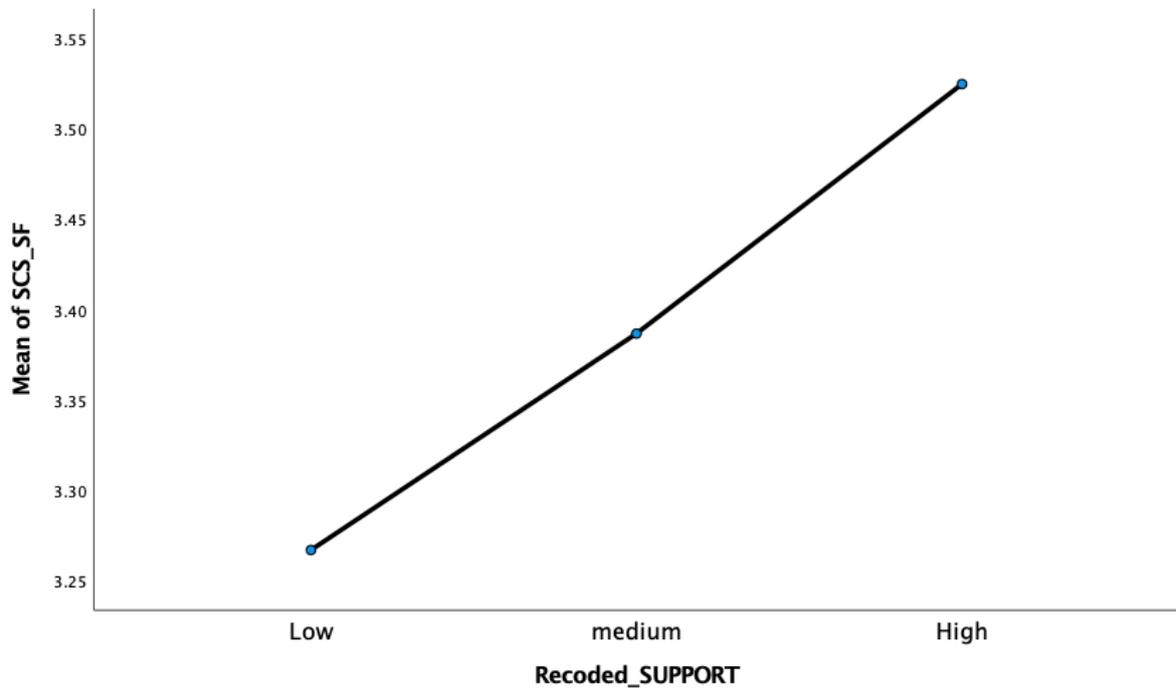   b. *Caregiving role as a barrier*

2. **Self-other compassion?**
    a. *Support being distressing for the recipient of care*
    b. *Risks of COVID-19*

3. **Other-self compassion**
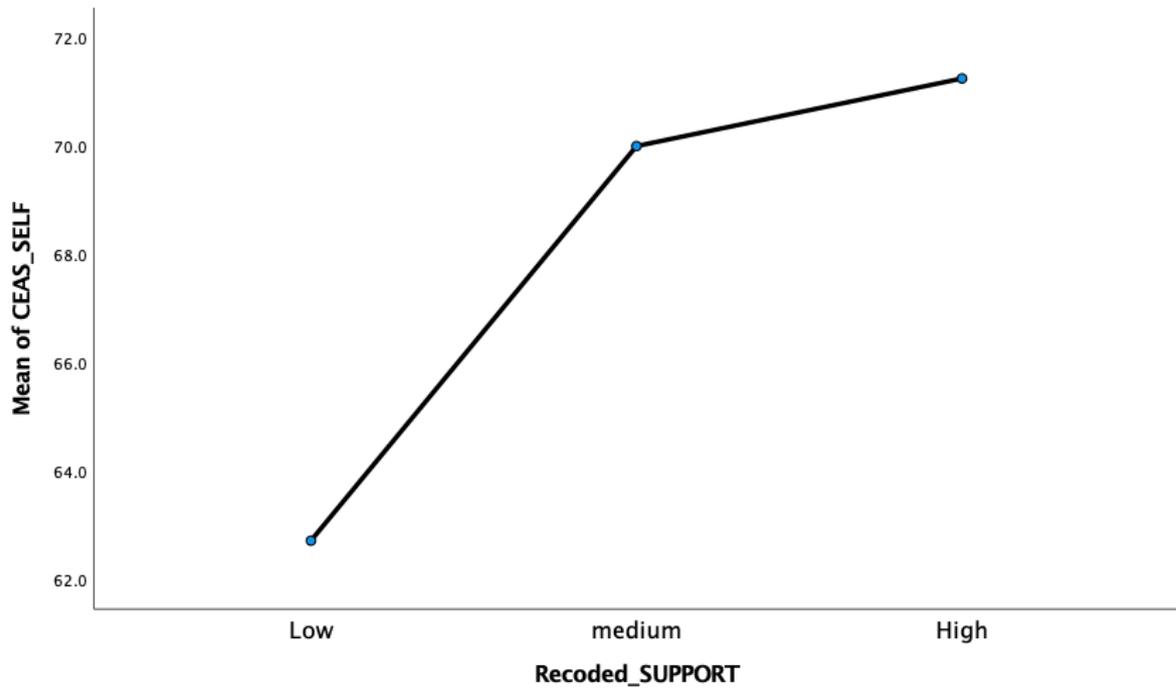   a. *Intrusive and antagonising*
    b. *Inappropriate support*
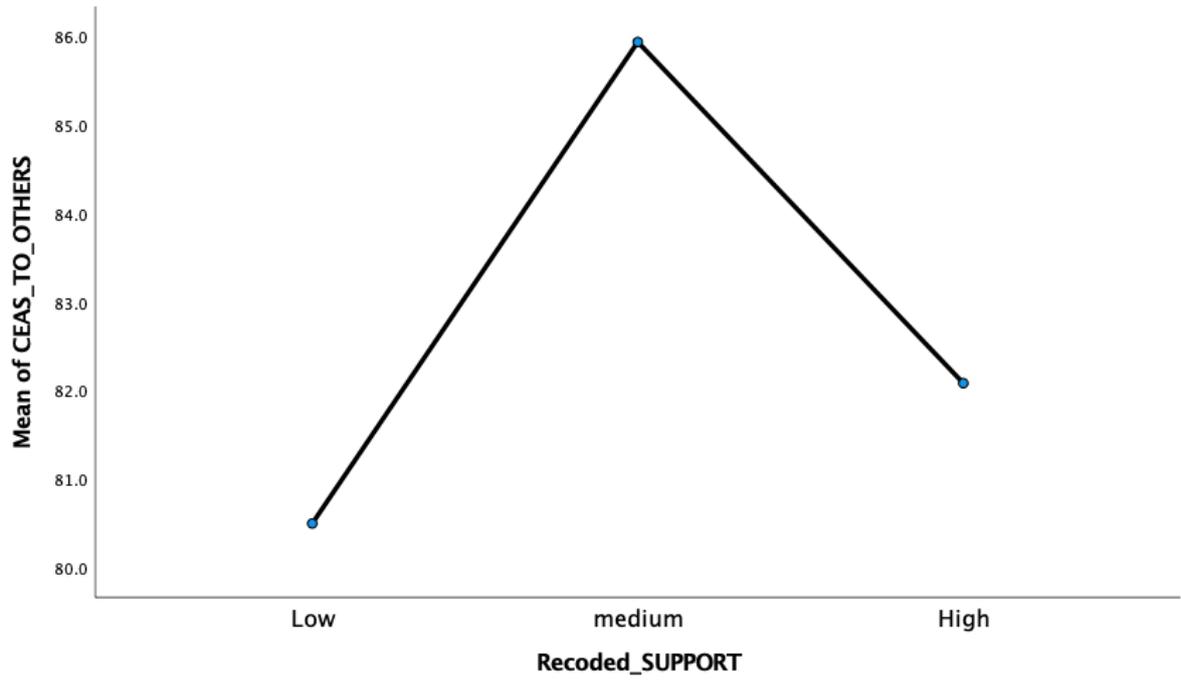   c. *Inaccessible services*
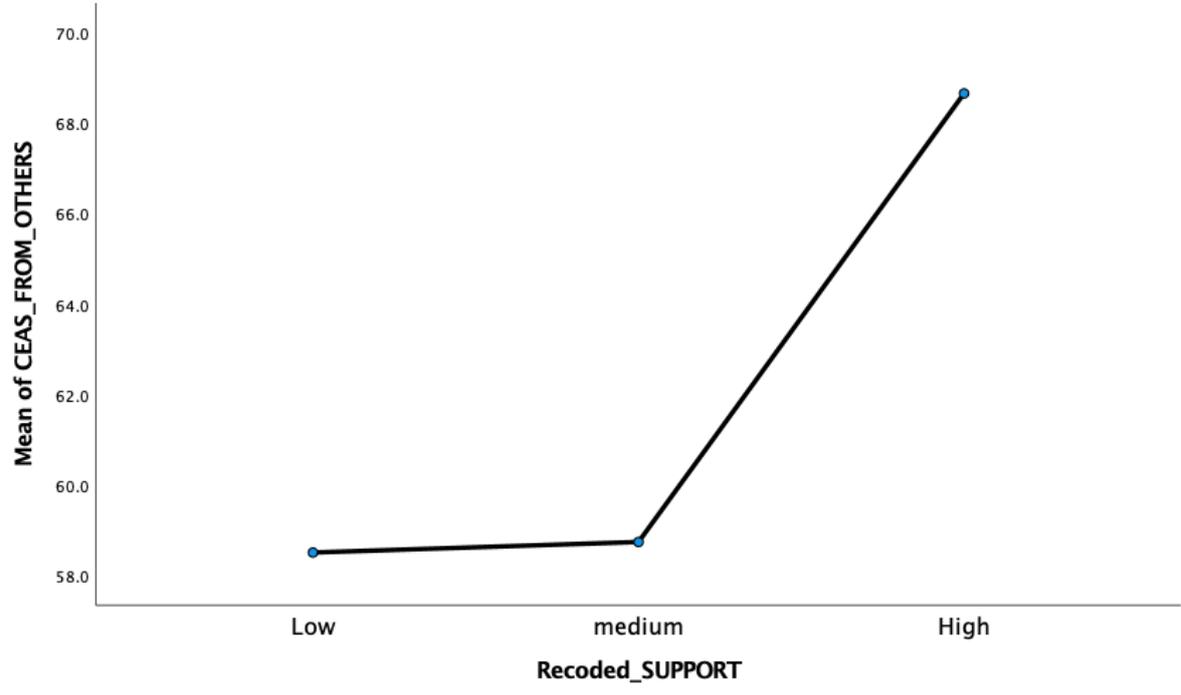
Appendix Q: Mean Plots

Graph 1. Mean of SCS-SF for each support use group.

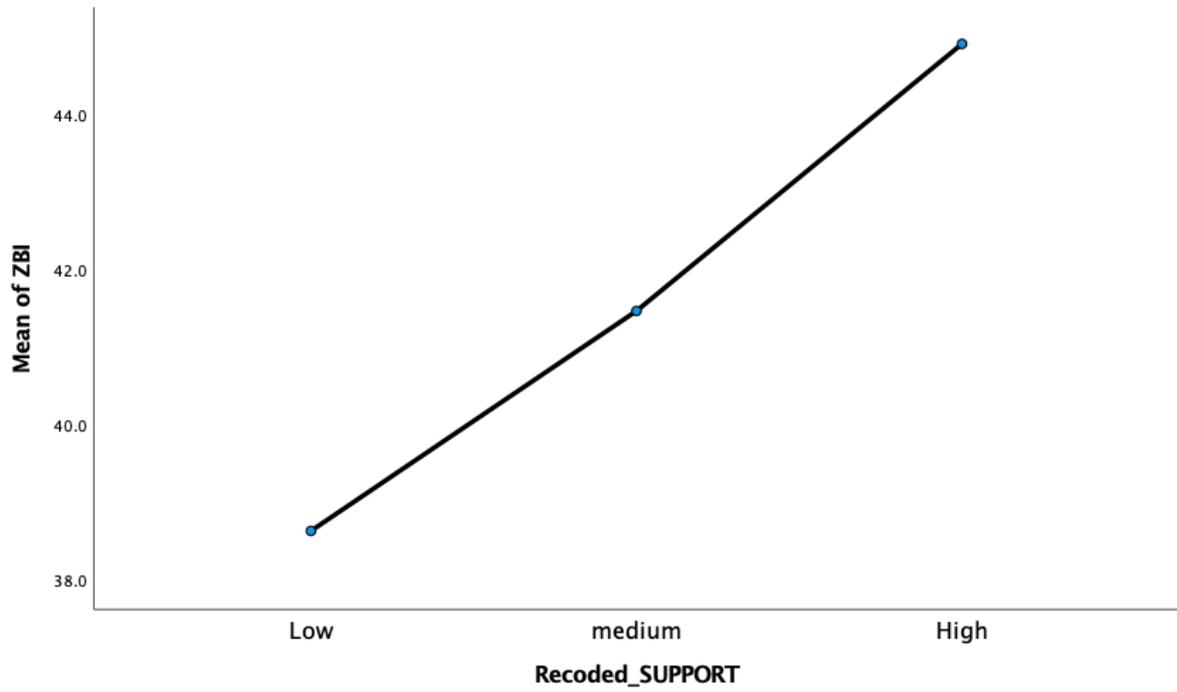Graph 2. Mean of CEAS-Self for each support use group.

Graph 3. Mean of CEAS-to others for each support use group.
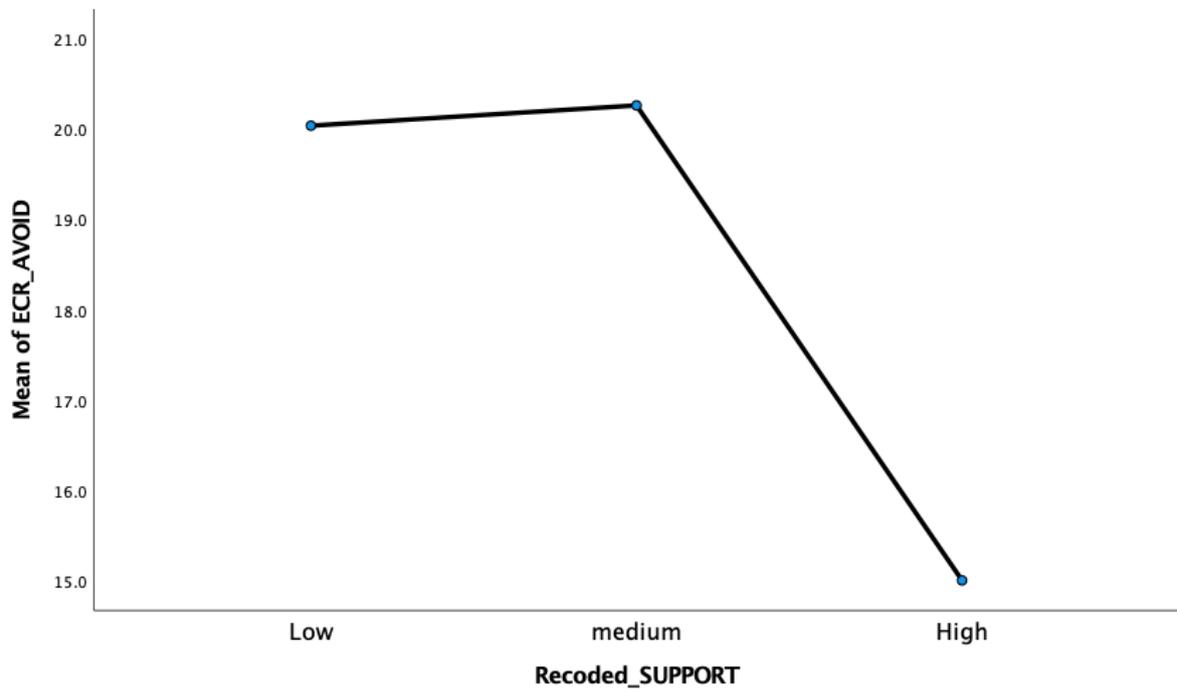

Graph 4. Mean of CEAS-from others for each support use group.

Graph 5. Mean of ZBI for each support use group.

Graph 6. Mean of ECR-Avoid for each support use group.

Graph 7. Mean of ECR-Anx for each support use group.