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Supporting positive experiences in caregivers of people living with dementia

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I would like to dedicate this research to the wonderful, hopeful, and essential people out in the world who devote their time to caring for loved ones living with dementia or other long term health conditions. The support you give and sacrifices you make are an invaluable aspect of what it means to be human.

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Overview

This thesis is divided into three parts: a systematic literature review, an empirical paper, and a set of appendices relating to both research projects.

Part One is a systematic literature review relating to wellbeing enhancing interventions for caregivers. Caregivers are known to experience marked stress, distress, and burden; therefore, it is important to understand how clinicians can work to support caregivers. This review aimed to examine current research evidence relating to wellbeing enhancing interventions for caregivers of people living with long-term health conditions. The review looked at eleven papers. The methodological quality of the papers has been evaluated. The findings of the review suggest that wellbeing enhancing interventions can be effective for caregivers, and that there continues to be limited application of positive psychology constructs within caregiver interventions. Furthermore, the review indicates that a single component positive psychology intervention may be more effective than multicomponent approach at enhancing caregiver wellbeing.

Part Two is an empirical study which investigates a positive psychology construct highlighted by the review for further exploration – hope. Hope is an area not currently focussed on in support for caregivers. The paper explores the views and experiences of caregivers of people living with dementia on how their process of renewing everyday hope could be supported. Five participants were interviewed, and thematic analysis was used to identify themes across their responses. The study identified five superordinate and four subordinate themes. The paper explores the importance of agency, grounding in reality, and solidarity in the community, and the implications supporting the enhancement of hope in caregivers of people living with dementia.

Part Three consists of the appendices relating to the research, including a reflective statement on the process of carrying out the research. The statement includes reflection on all aspects of research from design and planning to implementation of the research project.

List of Tables and Figures

Part One: Systematic Literature Review

Wellbeing enhancing interventions among caregivers of people living with chronic health conditions: A systematic review of literature

This paper was written in the format ready for submission to International Journal of Applied Positive Psychology (see Appendix G)

Word Count (including tables, figures, and references): 8053

Wellbeing enhancing interventions among caregivers of people living with chronic health conditions: A systematic review of literature

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Abbreviated title: A review of wellbeing enhancing interventions with caregivers

Abstract

Objectives: This review aimed to synthesise research into wellbeing enhancing interventions with caregivers, to understand the constructs being targeted and the effectiveness of existing intervention programs.

Method: Eleven papers were included within the review. The findings of each paper explored and synthesised using narrative synthesis. An evaluation of the methodological quality of the studies was conducted.

Results: There has been limited application of positive psychology constructs within intervention for caregivers, and a focus remains on evaluating reduction in negative constructs (e.g., depression) rather than improvement in positive ones (e.g., quality of life). Findings suggest that wellbeing enhancing intervention can be effective for caregivers.

Conclusion: A regular group intervention rooted in a specific positive psychology construct (e.g., hope, benefit-finding) may be more effective than a multicomponent approach at enhancing caregiver wellbeing. Further research into the effectiveness of specific positive psychology interventions (e.g., hope therapy) is needed to support the development of new interventions.

Keywords: wellbeing, intervention, caregivers, review

Introduction

'Positive psychology' advocates for a shift of perspective within psychology away from an historical position of studying dysfunction and weakness, toward viewing people and their experiences as being rooted in strength and virtue. Standing out from the other branches of the discipline, positive psychology encourages us to systematically examine positive experiences because psychologists should be working not just to fix what is wrong but to build upon what is right (Seligman, 2005). In recent years, global systems and institutions have begun to acknowledge the importance of attending to positive aspects of living, as reflected within the World Health Organisation's definition of mental health:

> *"Mental health is a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community"* (World Health Organisation, 2004, p. 12).

This shift can also be noted with regards to therapeutic work – positive psychological interventions (PPIs) – being developed and implemented across a range of clinical services and settings. PPIs may be defined for the purposes of this paper, as being any form of psychological intervention (therapy, training) where the primary aim has been stated as enhancing positive affect, positive cognitions or positive behaviours as opposed to interventions that aim to reduce symptoms, problems or disorders (Sin & Lyubomirsky, 2009). PPIs can therefore take a plethora of different forms, with the ultimate aim of the work to improve wellbeing and amplify the strengths, values and virtues held by an individual, group or system. Many studies have evaluated PPIs over the past few decades, with reviews having been conducted into the effectiveness of these interventions in enhancing wellbeing and reducing ‘depressive symptoms’ in clinical populations (Boiler et al., 2013; Sin & Lyubomirsky, 2009).

Although efforts have been made to evaluate wellbeing enhancing interventions, defining ‘wellbeing’ has been the subject of debate for some time. Dodge et al. (2012) took on this challenge and was able to amalgamate ideas from previous works (Cummins, 2010; Headey & Wearing, 1989; Hendry & Kloep, 2002) to produce a refreshed understanding. Their working definition is that wellbeing is a state of balance achieved between one’s resources and the challenges one faces. Drawing on theories and perspectives already published, Dodge and colleagues were able to develop a definition of wellbeing that places an emphasis on individuals having choices and the power to make decisions, with the ultimate aim being to maintain a state of equilibrium. In this respect, wellbeing can be likened to the concept of ‘happiness’, which is something that does not simply happen but is instead a state that requires cultivating in order to be achieved (Csikszentmihalyi, 2002). This definition has the benefit of being applicable to all aspects of one’s health – physical, psychological, and social – making it particularly useful within research into factors and circumstances that may affect someone’s wellbeing.

People living with chronic health difficulties are more likely to have lower wellbeing than those without (Raj et al., 2016). Chronic, or long-term, health conditions are physical health difficulties that cannot presently be cured and are instead only able to be managed by means of medication and/or other therapies (Department of Health, 2012). Almost nineteen million people in the UK live with chronic health conditions (Office for National Statistics; ONS, 2020). Naylor et al. (2012) estimate thirty percent of people with long-term health conditions also experience marked mental health difficulties and reduced quality of life. The importance of this link between the physical and psychological experiences of health has been acknowledged at a policy level in the UK, with ‘No Health Without Mental Health’ emphasising the need for services such as Improving Access to Psychological Therapies (IAPT) to step up their support for the psychological needs of people with long-term health conditions (Department of Health, 2011). However, current policies only focus on improving services for people living with chronic health, not those who care for and support them.

Unpaid ‘informal’ caregivers for people living with long term health conditions account for six percent of the British population (Department for Work and Pensions, 2022). The percentage of people who serve as informal caregivers differs around the world, with Germany reporting a smaller proportion of its population (5%; Robert Koch Institute, 2018), while the United States is believed to have a much greater number of caregivers (28%; National Alliance for Caregiving & American Association for Retired Persons, 2009). Informal caregivers are difficult to rigorously define, however, they could be considered anyone who does not receive direct payment or compensation for providing care (Greenwood et al., 2008), often referring to friends or family of the individual being cared for. Due to the nature of ‘the informal caregiver’, they typically provide care within a community setting (i.e., at home).

There have been previous reviews of the literature exploring the efficacy of PPIs for people living with chronic health conditions (Boiler et al., 2013), but they need updating and do not specifically address the experiences of caregivers. A review of the impact of PPIs among caregivers of people living with chronic health conditions, would aid with understanding which positive psychology constructs are currently being targeted by PPIs and the degree to which interventions are effective at enhancing the wellbeing of caregivers. A review such as this is useful given the link between caregiver wellbeing, the care provided (Hazzan et al., 2022; Litzelman et al., 2016) and care recipient wellbeing and quality of life. Therefore, by understanding how best to positively influence caregiver wellbeing, this could in turn improve care and outcomes for those being cared for, which may help to reduce the need for institutionalisation. Consequently, this could mean an easing of stresses upon the health and social care systems. We understand that there are positive aspects of caregiving (PACs), which may be derived from satisfaction in the caregiving relationship (Kramer, 1997; Tarlow et al., 2004). However, we need to better understand what positive factors might underpin wellbeing in caregivers, given how challenging this can be for people. Understanding what positive constructs to focus on is important for moving forward with supporting caregivers.

Aims

1. To review literature and highlight what positive psychology interventions have been used with caregivers.
2. To review literature and highlight what positive psychology constructs have been targeted by psychological interventions.
3. To identify what outcome measures have been used relating to wellbeing of caregivers.
4. To evaluate the effectiveness of psychological interventions on caregiver wellbeing.

Therefore, this review aimed to answer the following questions:

1. What positive psychology constructs have been targeted by psychological interventions used with caregivers?

2. What evidence is there to support the effectiveness of psychological interventions in improving caregiver wellbeing?

Method

Search Strategy

A systematic search was performed via EBSCOhost, facilitating access to the PsycINFO, CINAHL, MEDLINE and Academic Search Premier electronic databases, and manual searches of the reference lists and forward citations of all included studies. This extensive exploration of general, psychological, and medical databases, with additional manual searches, increased the likelihood of detecting all relevant articles. The search criteria adopted were as follows:

The search used terms divided into three categories: positive psychology, intervention studies, and caregivers. The applied search terms were as follows:

(positive psychol*) OR hope OR gratitude OR optimism OR resilience OR "self-efficacy" OR humo#r OR "wellbeing" OR (quality and life) OR "benefit finding"

AND

Intervent* OR therap*

AND

Carer* OR caregive* OR famil*

The search terms, particularly in relation to positive psychology, were drawn from previous reviews (see Boiler et al., 2013; Stansfeld et al., 2017; Wolverson et al., 2016). Three limiters were applied to the search so that articles were from academic journals to ensure they were of a higher quality and peer-reviewed; written in English for practicality due to the financial cost of translating services; and published after 1998 as this could be considered the start of the positive psychology movement (Seligman, 1998).

Manual searches were conducted of the reference lists of all included articles and a forward citation search using Google Scholar to ensure an extensive search of the literature.

Screening

The selection process was informed by the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement (Moher et al., 2009).

Table 1

Inclusion and exclusion criteria

Inclusion	Exclusion
Articles published from 1998 onwards due to this being considered the year in which positive psychology started as Martin Seligman, seen as the 'father of positive psychology', began publishing articles in this area.	Articles published prior to 1998.
Studies that evaluate psychological interventions that adhere to Sin and Lyubomirsky's (2009) definition of a positive psychological intervention; any	Non-intervention studies or intervention studies that are not in-line with the Sin & Lyubomirsky (2009) definition.

intervention with the primary aim of enhancing positive affect, cognitions, or behaviours.	
Studies that collected data using standardised, valid outcome measures relating directly to caregivers' wellbeing (e.g., quality of life, wellbeing specific measures), which would address the research question.	Studies that have made use only of informal, subjective outcome measures, which provide opinions of interventions. Studies that made use of standardised measures that do not focus on wellbeing or associated positive constructs, including measures of negative constructs (e.g., depression, distress).
Peer-reviewed journal articles.	Reviews or discussion articles.
Articles are published in English.	Articles published in any language other than English due to financial restrictions on accessing comprehensive translation services and English being the language used by the researchers.
Participants are identified as fitting with Greenwood et al.'s (2008) definition of an informal caregiver; an individual that does not receive payment or direct financial compensation for the care they provide. Participants must be providing care to someone living with at least one long-	Participants are identified as being formally employed to, or directly paid or compensated for, providing care. Participants provided short-term care to someone experiencing adverse physical or mental health, which is not deemed to be terminal, enduring or incurable (for example, recovering from routine surgery).

term (chronic) health condition, as characterised by the Department of Health (2012) definition of long-term health conditions used within this review (for example, dementia, chronic heart disease, AIDS).	
Papers looking at people with long term conditions and their caregivers, but where it is possible to extract just caregiver data.	

Quality Assessment

The quality of the studies included in the final review pool was assessed using the Effective Public Health Practice Project's Quality Assessment Tool for Quantitative Studies (Armijo-Olivo et al., 2012; Thomas et al., 2004; see Appendix A). This tool was chosen due to its easy application and ability to provide a broad evaluation of methodological quality, covering several key areas. The quality assessment tool was utilised to evaluate the methodological quality across six primary domains (see Appendix B for domain meanings), which culminated in an overall global rating being assigned for each paper. No papers were excluded based on the overall scores as all studies made a beneficial contribution to the review and provided insight into the quality of research currently available. As a check of rater reliability, four paper from across the quality ratings were assessed by a peer reviewer, blind to the original ratings. The level of agreement on ratings was 96%, minor discrepancies were discussed, and agreement reached regarding the final ratings. The final quality ratings can be found in Appendix C.

Data Extraction

Information relevant to the review questions was extracted from each study using a bespoke data extraction table (see Table 2). Data extraction involved identification of the articles' design, research aims, participants demographics, intervention type, outcome measures and key findings. These key features of each study were needed to generate a broad understanding and answer the review questions.

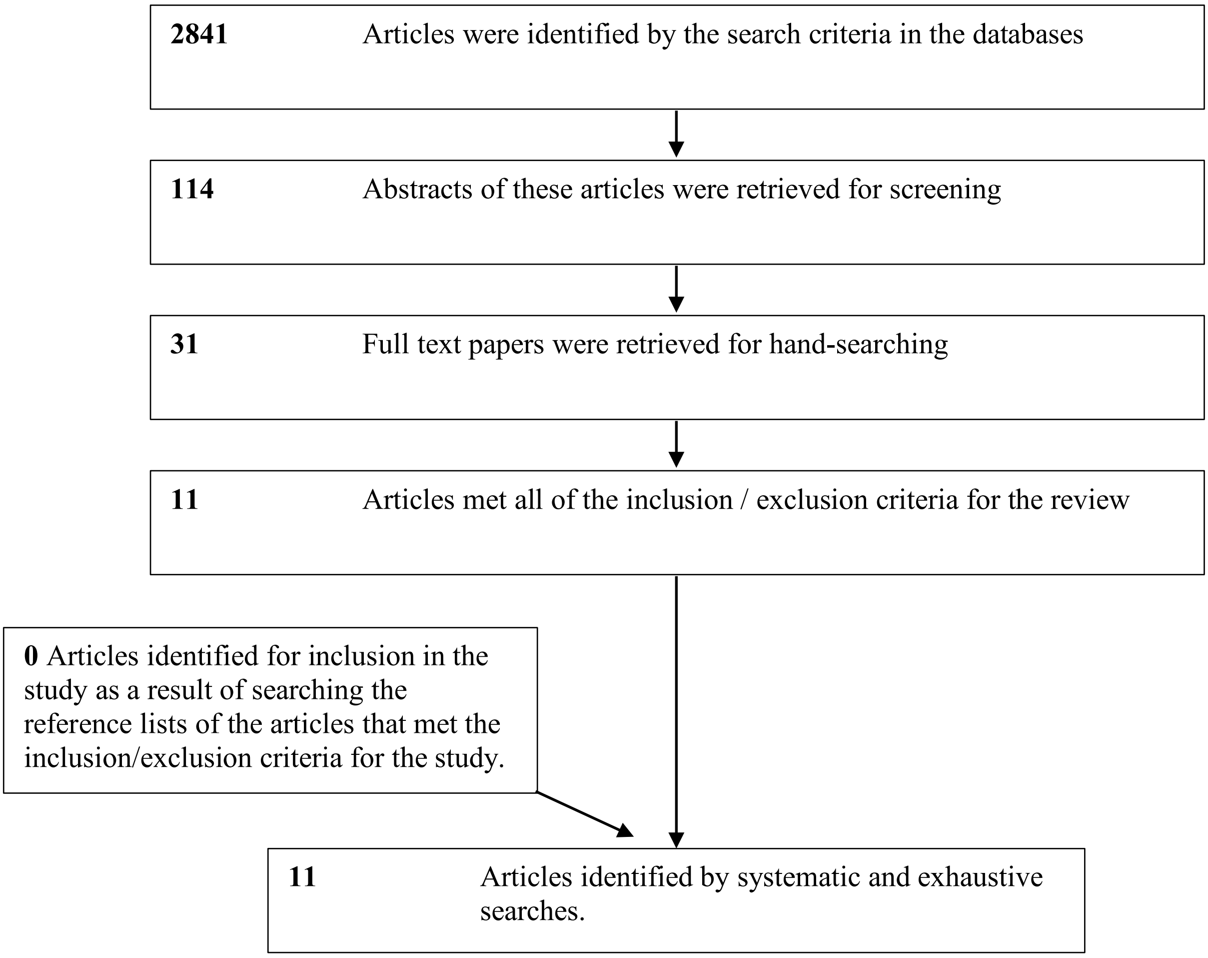
Data Synthesis

The reviewed studies varied with regards to the intervention employed and the measures used to evaluate effectiveness, therefore, a meta-analysis was inappropriate. Thematic synthesis is designed mainly for use with qualitative data, rather than analysing quantitative findings (Thomas & Harden, 2008), and was therefore not considered in this review. Narrative synthesis allows for the compilation and consolidation of associated literature from which potential themes can be drawn out (Popay et al., 2006). Narrative synthesis is particularly well-suited for use when the included studies have considerable methodological variation (Lucas et al., 2007), as in this review. In line with Popay et al.'s (2006) guidance, initial themes were drawn from relevant characteristics extracted from the findings of each study, followed by the identification of emerging patterns across the themes. Factors were identified across the studies that might explain differences in effect size and direction (e.g., variability in design, outcomes, intervention implementation, etc.). The quality of the reviewed studies was assessed as a means of evaluating the robustness of the synthesis.

Results

Figure 1

Summary of search and selection process



2841 Articles were identified by the search criteria in the databases

114 Abstracts of these articles were retrieved for screening

31 Full text papers were retrieved for hand-searching

11 Articles met all of the inclusion / exclusion criteria for the review

0 Articles identified for inclusion in the study as a result of searching the reference lists of the articles that met the inclusion/exclusion criteria for the study.

11 Articles identified by systematic and exhaustive searches.

Descriptive Characteristics of Studies

In total, eleven quantitative studies were included in the review (see Table 2). The studies were published between 2013-2021, with only three published before 2019 (Barog et al., 2015; Bartfay & Bartfay, 2013; Norouzi et al., 2014). Several countries were represented, although all from the northern hemisphere: four from Iran, three from China (including two from Hong Kong), and one study each from Canada, Ireland, Germany, and the Netherlands.

All included studies captured caregiver experiences in relation to concepts associated with wellbeing, however, only two studies directly measured the concept of wellbeing (Cheng et al., 2019; Cheng et al., 2020). All articles explored the effect of psychologically informed interventions on improving caregiver quality of life, which was directly measured in all cases.

The total number of participants across the articles, derived from ten unique samples, was 1092. Sample sizes ranged from three to 319 participants. All studies reported participant gender, which were predominantly female caregivers, with 851 women and 241 men.

The included articles covered a range of chronic health conditions, with people living with and receiving care related to dementia in six studies (including four for Alzheimer’s disease), and one article each for multiple sclerosis (Azimian et al., 2021), cerebral palsy (Barog et al., 2015), stroke (Fu et al., 2020), and diabetes and chronic kidney disease together (Mowla et al., 2020). Gallagher et al. (2020) did not specify any health conditions.

Table 2

Summary of the characteristics of articles reviewed

Author(s), Year & Country	Aims	Design	Sample	Intervention	Measures (construct evaluated)	Findings	Quality Rating
Azimian et al. (2021) Iran	Evaluate group hope therapy training effectiveness on quality and meaning of life	Pre-post-test experimental, with control group	N=60 (30 caregivers, 30 patients) Multiple sclerosis (MS)	Group hope therapy 8 sessions	IRQOL (quality of life) MLQ (meaning in life)	Group hope therapy did not increase patient QoL. Group hope therapy significantly increased family caregiver QoL, with high efficacy indicated. Pre-test (59.40) to post-test (70.33) for QoL in caregiver-experimental.	Weak

						Pre-test (14.73) to post-test (20.73) for presence of meaning in caregiver-experimental. Pre-test (16.06) to post-test (31.06) for search for meaning in caregiver-experimental.	
Barog et al. (2015) Iran	Investigate the effect of MBCT on caregiver quality of life.	Single-case experimental	N=3 mothers Cerebral palsy (CP)	MBCT 8 sessions	WHOQOL-BREF (quality of life)	All three participants showed positive improvement in WHOQOL-BREF scores from baseline to post-test scores. Improvements were seen across all four domains; physical health, psychological, environment, and social relations.	Moderate

Bartfay & Bartfay (2013) Canada	Examine effect of community-based interventions on caregiver quality of life	Cross-sectional comparative pilot study	N=62 Alzheimer's disease	Caregiver support group (direct) Adult day programs for care recipients (indirect)	QOL-AD (quality of life)	Support group caregivers had higher QoL ratings (2.9) than caregivers of AD day program clients (2.76), however, this was not statistically significant. On specific QoL ratings, support group caregivers reported more favourably in ‘memory’ and ‘ability to have fun’ categories compared to the other groups.	Moderate
Cheng et al. (2019) Hong Kong	Examine effects of group BFT on family caregivers	Cluster-randomised double-blind	N=129 caregivers Alzheimer's disease	BFT 8 sessions	HDRS (depression)	BFT superior to SIM-PE and STD-PE in reducing depressive symptoms.	Moderate

		controlled trial			Pearlin ROM (role overload) ZBI (burden) Ryff’s Psychological Wellbeing Scale	BFT had no observable effect on role overload, however, there was a small positive effect of BFT on global burden compared to SIM-PE, including at T3 and T4. BFT had a greater effect on psychological wellbeing than SIM-PE at all time points, however, BFT was only superior to STD-PE at T4.	
Cheng et al. (2020) Hong Kong	Examine longer-term effects of benefit-finding on caregivers	Randomised double-blind controlled trial	N=96 caregivers Alzheimer’s disease	BFT 8 sessions	HDRS (depression) Pearlin ROM (role overload)	4 month follow up showed substantial reductions in depressive symptoms compared to controls.	Moderate

					ZBI (burden) Ryff’s Psychological Wellbeing Scale	Positive aspects of caregiving showed intervention effect at 10 month follow up.	
Fu et al. (2020) China	Evaluate effectiveness and feasibility of BFT for caregivers	Parallel randomsied single-blind controlled trial	N=68 caregivers Stroke	BFT 9 sessions	PBFoC (benefits of caregiving) ZBI (burden) AC-QoL (quality of life)	Significantly higher total score and individual dimension scores on the PBFoC in the intervention group, compared to the controls. Total score and all dimensions of ZBI decreased from T1 to T2. Total score and all dimensions of ACQoL were significantly higher at	Moderate

						T2 in intervention group than control.	
Gallagher et al. (2020) Ireland	Evaluate the feasibility and acceptability of a brief benefit-finding writing intervention for caregivers	Parallel randomsied double-blind controlled trial	N=88 caregivers Health condition(s) not specified	Benefit finding intervention 6 sessions	BFS (benefit-finding) AC-QoL (quality of life) HADS (depression & anxiety)	No effect seen on any outcomes measured.	Moderate
Meichsner et al. (2019) Germany	Examined the effects of telephone-based	Randomised controlled trial	N=273 caregivers Dementia	CBT 12 sessions	WHOQOL-BREF (quality of life)	Intervention group mean scores increased across all measured domains from T0 to T1, and the increase for overall QoL was	Moderate

	CBT on caregiver quality of life					statistically significant compared with the control group. Effect not considered maintained at T2, however, T2 mean scores remained higher than T0.	
Mowla et al. (2020) Iran	Examine the effects of combination of BRT and brief psychoeducation on religious coping and quality of life in family caregivers	Pre-post-test experimental, with control group	N=100 caregivers Diabetes & chronic kidney disease	BRT & psychoeducation 4 sessions	Brief RCOPE (religious coping) SOC-13 (sense of coherence) SF-36 (quality of life)	Positive RCOPE, SOC and quality of life (SF-36) – physical and mental components – increased from T0 to T2 for the intervention group, with significant increases seen four weeks post-intervention for QoL.	Moderate

Norouzi et al. (2014) Iran	Examine effectiveness of MBCT on easing burden and improving quality of life in caregivers	Pre-post-test experimental, with control group	N=20 caregivers Alzheimer's disease	MBCT 8 sessions	HDRS (depression) SF-36 (quality of life) CBI (burden)	Mean scores for experimental group quality of life increased from pre-test (58.01) to post-test (70.98), however, control group decreased. Experimental follow up scores were also higher than pre-test (68.93). Mean depression scores for experimental group decreased from pre-test (20) to post-test (6.7) and decreased again at follow up (4.2). Control group scores increased at post-test. Mean burden scores for experimental group decreased from pre-test (31.6) to post-test (24), and	Weak

						again at follow up (17.6). Control group scores increased.	
Van der Heide et al. (2021) Netherlands	Evaluate the effect of educational peer group intervention on family caregivers	Cluster randomised controlled trial	N=319 caregivers Dementia	Psychoeducation peer group intervention 2 sessions	COOP/WONCA charts (functional health) SPPIC (self-perceived pressure)	In intervention group, mean perceived emotional problems score at T1 significantly lower than T0. However, T2 mean score was higher than T0. No significant differences over time in control. Increased mean scores for hampered social activities in intervention and control, but not significant.	Strong

Small but significant improvement in perceived general health status in intervention group. T0 to T1 was not significant, however, T0 to T2 was. Decrease was not present in control, who instead had non-significant increase.

CBT, Cognitive Behavioural Therapy; MBCT, Mindfulness-based Cognitive Therapy; BFT, Benefit-finding Therapy; BRT, Benson's Relaxation Technique

Quality

Assessment of methodological quality resulted in one paper being graded as ‘strong’, meaning that no items from the checklist were rated as ‘weak’. Eight papers were graded as ‘moderate’, meaning that they were given only one ‘weak’ rating, with the remaining ratings being either ‘strong’ or ‘moderate’. Two studies (Azimian et al., 2021; Norouzi et al., 2014) were graded as ‘weak’ due to having two or more ‘weak’ ratings across the checklist criteria. Appendix C demonstrates a breakdown of specific checklist item ratings for each paper.

Explanations of blindness within the studies varied. Blindness refers to the extent to which parties within the study are aware of key information relating to the research’s aims and design, which could potentially bias those involved. Some papers were explicit in how blinding worked (Cheng et al., 2019; Cheng et al., 2020; Gallagher et al., 2020). However, most papers were not clear or demonstrated poor blinding in their designs.

In terms of data collection and reporting of withdrawals, papers were rated as ‘strong’ across the board, except for Gallagher et al. (2020) who experienced a high rate of dropouts.

Interventions

Administration of the interventions was primarily face-to-face, with only Meichsner et al. (2019) using telephone contact as the medium of communication.

The included studies varied in terms of how interventions were delivered with six studies utilising group interventions (Azimian et al., 2021; Bartfay & Bartfay, 2013; Cheng et al., 2019; Cheng et al., 2020; Mowla et al., 2020; van der Heide et al.,

2021) and five making use of one-to-one approaches (Barog et al., 2015; Fu et al., 2020; Gallagher et al., 2020; Meichsner et al., 2019; Norouzi et al., 2014).

Eight studies involved an intervention taking a cognitive stance (i.e., aimed to alter thoughts or behaviours), while two opted for a psychoeducational approach (Mowla et al., 2020; van der Heide et al., 2021) and one study's intervention took the form of an informal and unstructured discussion (Bartfay & Bartfay, 2013). The eight studies who structured their interventions cognitively – meaning they focused on modifying cognitions and behaviours – did so from a range of conceptual standpoints (see Table 3). Both psychoeducational interventions (Mowla et al., 2020; van der Heide et al., 2021) provided caregivers with information about the relevant chronic health conditions, caring techniques and local support services. Mowla et al. (2020) also provided information about anxiety and how to manage this, in addition to how to change one's lifestyle to improve health and wellbeing.

Table 3

Summary of cognitively informed intervention programs

Intervention	Representative studies
Hope therapy	Azimian et al. (2021)
Mindfulness-based cognitive therapy (MBCT)	Barog et al. (2015) Norouzi et al. (2014)
Cognitive behavioural therapy (CBT)	Meichsner et al. (2019)
Benefit-finding intervention	Cheng et al. (2019) Cheng et al. (2020) Fu et al. (2020)

Gallagher et al. (2020)

The length of intervention (number, frequency, and duration of sessions) provided and the times at which measures were administered varied across the studies.

With regards to the number of sessions, five studies (Azimian et al., 2021; Barog et al., 2015; Cheng et al., 2019; Cheng et al., 2020; Norouzi et al., 2014) provided 8 intervention sessions to caregivers. The remaining studies provided 12 sessions (Meichsner et al., 2019), 9 sessions (Fu et al., 2020), 6 sessions (Gallagher et al., 2020), 4 sessions (Mowla et al., 2020), or 2 sessions (van der Heide et al., 2021). Bartfay and Bartfay (2013) did not report the total number of sessions attended by caregivers.

Five studies (Barog et al., 2015; Cheng et al., 2019; Cheng et al., 2020; Fu et al., 2020; Norouzi et al., 2014) provided the intervention on a weekly basis. Meichsner et al. (2019) and van der Heide et al. (2021) delivered their respective interventions every two weeks, while Bartfay and Bartfay (2013)'s participants engaged monthly. Two studies provided interventions involving multiple sessions per week (Gallagher et al., 2020; Mowla et al., 2020). Azimian et al. (2021) did not report the frequency of intervention sessions.

Session duration ranged from 45 minutes to 2 hours 30 minutes. Two studies involved sessions lasting less than an hour (Fu et al., 2020; Meichsner et al., 2019), three studies' sessions lasted for 1 hour or slightly over (Barog et al., 2015; Bartfay & Bartfay, 2013; Mowla et al., 2020), and five studies had sessions lasting in excess of

1 hour 30 minutes with an average of 2 hours (Azimian et al., 2021; Cheng et al., 2019; Cheng et al., 2020; Norouzi et al., 2014; van der Heide et al., 2021). Gallagher et al. (2020) did not report session durations.

Constructs Targeted

Five papers utilised specific positive psychology constructs (Seligman, 2005) to define the design of their interventions. Azimian and colleagues (2021) targeted hope within their group intervention, while benefit-finding was targeted by the other four papers (Cheng et al., 2019; Cheng et al., 2020; Fu et al., 2020; Gallagher et al., 2020). Barog et al. (2015) and Norouzi et al. (2014) embedded mindfulness within their intervention designs. The remaining papers utilised either cognitive or psychoeducational approaches without focusing on a key psychological construct (Bartfay & Bartfay, 2013; Meichsner et al., 2019; Mowla et al., 2020; van der Heide et al., 2021).

Outcome Domains

Eighteen outcome measures were used across the included studies, covering nine conceptual domains: quality of life, burden, depression, wellbeing, benefit-finding, sense of coherence, religious coping, meaning in life, and overall functional health.

The World Health Organisation’s brief quality of life measure (WHOQOL-BREF; Skevington et al., 2004), Iranian quality of life questionnaire (IRQOL), quality of life-Alzheimer’s disease scale (QOL-AD; Logsdon et al., 1999), adult carer quality of life questionnaire (AC-QOL; Joseph et al., 2012), and the 36-item short form survey

(SF-36; Ware, 1999; Ware, 2000) were used to assess caregiver quality of life in eight of the reviewed articles.

Five studies employed the following measures to assess caregiver experiences of burden: the Pearlin role overload measure (Pearlin ROM; Pearlin et al., 1990), Zarit Burden Interview (ZBI; Zarit et al., 1986), Caregiver Burden Inventory (CBI; Novak & Guest, 1989), and the Self-perceived Pressure from Informal Care scale (SPPIC; Pot et al., 1995). The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and Hamilton Depression Rating Scale (HDRS; Hamilton, 1960) were used to assess levels of caregiver low mood/depression in four studies.

Wellbeing was only directly assessed in two articles, using Ryff's Scales of Psychological Wellbeing (Ryff, 1989; Ryff & Keyes, 1995). Benefit-finding was measured by two of the reviewed studies using the Benefit Finding Scale (BFS; Antoni et al., 2001) and the Perceived Benefits of Caregiving scale (PBFoC; Beach et al., 2000).

Meaning in life, religious coping, sense of coherence, and overall functional health were each measured using only one tool. Respectively, these measures were: the Meaning in Life Questionnaire (MLQ; Steger et al., 2006), the brief religious and spiritual coping scale (Brief RCOPE; Pargament et al., 2011), the 13-item Sense of Coherence scale (SOC-13; Antonovsky, 1987; 1993), and the Dartmouth primary Care Cooperative Research Network/World Organisation of National Colleges, Academies and Academic Associations of General Practitioners and Family Physicians (COOP/WONCA) charts. These measures were used across five of the included articles.

Effectiveness of Interventions

Improvements in outcomes were observed in nine of the eleven papers reviewed. Gallagher et al. (2020) found their benefit-finding intervention to have no effect on outcomes, and while van der Heide et al. (2021) initially observed an improvement from T0 to T1, they then witnessed a decline at T2 with scores worse than at T0. Effect sizes varied across studies, with some being small but consistent with previous findings (e.g., Meichsner et al., 2019) and other's reaching $d = 0.90$ (e.g., Barog et al., 2015). Seven papers exhibited some degree of significance in changes in outcomes (Azimian et al., 2021; Barog et al., 2015; Cheng et al., 2019; Cheng et al., 2020; Fu et al., 2020; Meichsner et al., 2019; Mowla et al., 2020), while Bartfay and Bartfay (2013) and Norouzi et al. (2014) demonstrated no significance despite noted differences in outcome scores.

Where studies demonstrated improvement in outcomes, these are noted across all measures utilised within the respective papers. The most significant improvements in outcomes were seen in cognitively focused interventions (Azimian et al., 2021; Barog et al., 2015; Cheng et al., 2019; Cheng et al., 2020; Fu et al., 2020). Only two studies (Mowla et al., 2020; van der Heide et al., 2021) employed a psychoeducational approach, which had a mixed impact. Mowla et al. (2020) found positive changes in outcomes, which were either not statistically significant, minimally significant, or not sustained longer-term.

Discussion

Overview of Findings

This systematic review aimed to explore the psychological interventions being used with caregivers and their effectiveness at improving experiences of wellbeing, including the identification of specific constructs targeted and how outcomes were measured. The review identified that current psychological interventions do have a degree of effectiveness in improving caregiver wellbeing. It was noted that the majority of interventions, based on those reviewed, do not make use of specific positive psychology constructs within their design. Whilst some indirect measures of wellbeing, mainly quality of life, are being implemented in research and practice, there remains a clear focus on the use of negative constructs (e.g., depression, burden, stress) for evaluating change in caregiving wellbeing.

Psychological Constructs Targeted

The reviewed papers identified that the respective interventions ultimately aimed to improve the wellbeing of caregivers, however, the specific constructs targeted by said interventions varied. With respect to the application of positive psychological constructs within interventions, only a small number of the examined papers utilised interventions that would target a specified positive psychological concept. Hope and benefit-finding were imbedded into interventions, in addition to being involved in outcome measures. Although identifying the aim of the interventions to be improving caregiver wellbeing, most of the reviewed papers lacked a positive focus within the constructs targeted, which was further reflected within the outcome measure applied.

Effectiveness of Interventions

With quality of life being the primary indicator of wellbeing across the studies, this review's results present evidence that psychological interventions can be effective in enhancing caregiver wellbeing. However, the degree to which interventions were effective varied across the studies, suggesting that certain approaches are more successful in targeting the concept of wellbeing, and that more exploration of how and why this happens is needed.

When considering all aspects of the evaluated interventions (effect size, significance, method of delivery, theoretical focus, use of positive psychological constructs, etc.), this review suggests the available evidence indicates a group intervention that is cognitively orientated and makes use of a single positive psychology construct (e.g., hope, benefit-finding) may be the most effective approach to improving caregiver wellbeing. The review suggests that individual (i.e., one-to-one) interventions that are cognitively orientated and utilise positive psychology constructs are the next most effective, as they proved to have a greater effect on wellbeing than individual cognitive interventions that were not underpinned by positive psychology within the therapy program. When exploring the nuances between studies and their chosen therapeutic methods, the findings lend support to the idea that a focus on positive psychology is more beneficial than focussing on a reduction in negative constructs (e.g., burden, anxiety, depression). This review could be seen to support the points put forward by Boiler et al. (2013) regarding the use of positive psychological interventions for enhancing wellbeing.

With respect to psychoeducation, similar findings were demonstrated in Lee et al.'s (2020) review, which could be interpreted as psychoeducational approaches being of little benefit to the population in question. However, there is research to suggest benefits of an education program, including its ability to encourage engagement in therapy (Livingston et al., 2013). Likewise, the findings of this review do not show psychoeducation to be ineffective, but instead suggest that it may be less effective when compared to more cognitive therapies. However, consideration must be made the small sample within the present review.

Measuring the Concept of 'Wellbeing'

In the reviewed papers, wellbeing was examined from both a positive (i.e., enhancing, improving, encouraging) and negative (i.e., reducing, decreasing, minimising) position. Most research and clinical practice guidance have historically emphasised the aim of reducing or eradicating negative experiences, which for caregiver populations could include (but not be limited to) depression, anxiety, burden, stress, and burnout. Although quality of life was used in majority of the reviewed papers to indicate wellbeing, there remained a stark focus across the reviewed literature on measuring from a negative position, with measures of depression, burden and caregiver stress. As much of the reviewed literature was published within the last decade, this may indicate that less progress has been made within psychology toward focusing on strengths and virtues than would have been expected.

Limitations

Although the inclusion of research from across North America, Europe and Asia can be viewed as a strength, the extent of variation between the studies may suggest comparison across continents is inappropriate. To illustrate this, consider Azimian et al's (2021) use of hope therapy; this research was conducted in Iran, however this has a vastly different culture and societal structure to that of Western

Europe or Hong Kong. Cultural and sub-cultural nuances will have impacted on the application and effectiveness of interventions in these different countries, further contributing to the complexities of drawing conclusions and generalising universally. Evaluations of effectiveness for individual interventions need to consider the implications of local culture on outcomes.

Differences across the studies regarding outcome measures used, including when measuring the same concept, could account for discrepancies in observed outcomes changes following engagement in the interventions. Such inconsistencies in the evaluation of changes across intervention protocols also contributed to the differences in quality of the papers.

The articles included in this review did not share a singular, accepted definition of wellbeing. Therefore, these articles measured wellbeing in vastly different ways, targeting other distinct concepts that can be associated with wellbeing but do not provide a complete view. These differences mean that this review's findings need to be considered with caution, pending further research.

Clinical Implications and Future Research

This review offers an improved understanding of positive psychological interventions that may help development of future therapy programs for enhancing and maintaining wellbeing amongst caregivers.

To build on the findings of this review, further research is needed in the following areas:

- Research to develop an understanding of the value and importance different positive psychology constructs can have on a person's overall wellbeing, enabling the potential core concepts of future interventions to be identified.
- Continue to explore the effectiveness of intervention on wellbeing with specific groups of caregivers, such as caregivers of people living with dementia, to reflect the rate of growth of this community and due to the experienced burden and distress being greater than any other caregiver group (Brodaty & Donkin, 2009).
- Develop an understanding of cultural nuances with respect to psychological interventions amongst caregivers, enabling adjustments to be made that facilitate better application of the therapy programs globally. Studies co-produced with carers could aid with accounting for and exploring such nuances.

Conclusion

This review helps to support the arguments made by the positive psychology movement; that a shift in favour of enhancing and maintaining positive experiences (i.e., hope, resilience, gratitude) rather than focusing on a reduction in distress is the correct course of action for improving mental health services, and consequently, changing societal expectations and perspectives on differences and difficulties encountered by care givers and recipients. Facilitating deeper understandings of the potential for positive living should be seen as an essential cornerstone to successful management of societal discourses regarding care. Although this review had a small sample, the available data indicates that a group intervention with a single positive psychology component approach may produce the most meaningful change with regards to caregiver wellbeing.

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Part Two: Empirical Paper

Enhancing experiences of hope in caregivers of people living with dementia: An exploratory study

This paper was written in the format ready for submission to Dementia (see Appendix H)

Word Count (excluding references): 5697

Enhancing experiences of hope in caregivers of people living with dementia: An exploratory study

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Abstract

Objectives: Caring for someone living with dementia can be stressful and emotionally difficult, but there are also positive aspects of caregiving. Hope is an area that is not focussed on in current support for caregivers. Therefore, this study aimed to understand the views and experiences of caregivers of people living with dementia on how their process of renewing everyday hope could be supported. *Method:* Five caregivers of people living with dementia were recruited opportunistically. Semi-structured interviews were used to explore participants' views and experiences of hope, particularly in terms of their personal meaning, and how the daily process of renewing hope has or can be supported. Interviews were analysed using Thematic Analysis. *Results:* Five themes were developed, with two themes having two subthemes each, which included "Education", "Practical Support", "Accepting Circumstances and Adapting Goals", "The Importance of Others' Support", and "Focussing on Self". *Conclusion:* This research highlights the importance caregivers of people living with dementia place on having agency, timely access to information that grounds them in reality, and a sense of solidarity and recognition within their community. Implications for strengthening and developing existing service provisions emerged.

Keywords: hope, caregivers, dementia

Introduction

More than 670,000 individuals act as a caregiver to persons living with dementia in the UK (Carers Trust, 2019; Lakey et al., 2012; Lewis et al., 2014). A continually ageing population is driving the increased prevalence of dementia (Prince et al., 2015), which ultimately results in an increasing population of caregivers. Dementia can have a profound impact on a person's life, and as a person living with dementia's support needs increase, caregiver quality of life can decrease (Haley et al., 2000; Kristianson et al., 2006). Caregivers of people living with dementia, in particular, are believed to experience higher levels of stress and burden (Brodaty & Donkin, 2009) compared with other carer populations, with caregiver burden being a key indicator of early placement into residential care for the person living with dementia (Etters et al., 2008). Ensuring persons living with dementia have their time living at home maximised is important as the literature suggests that quality of life is greater at home than when receiving residential care (Nikmat et al., 2015). This may in part be because people living with dementia, and their families, prefer to remain at home for as long as possible (Lord et al., 2016).

Being a caregiver is not a wholly negative experience. Positive aspects of caregiving (PACs) refers to the rewards and satisfactions derived from the caregiver relationship (Kramer, 1997; Tarlow et al., 2004). Some literature suggests feelings of satisfaction and reward within the caregiving experience may reduce caring-related stress and improve emotional outcomes (Kinney & Stephens, 1989; Roff et al., 2004). Therefore, the PACs should be considered when providing caregivers with support, as this support should both reduce the difficulties being faced and enhance the positive aspects of the caregiver's role (Levesque et al., 2002; Louderback, 2000; Nolan et al., 1996; Nolan et al., 2003). A more positive experience of caregiving could assist with the maintenance of caregiver involvement and providing better care (Hazzan et al., 2022; Litzelman et al., 2016), thus delaying institutionalisation of persons living with dementia, which may in turn contribute to the maintenance of quality of life and wellbeing in people living with dementia.

A positive experience of caregiving could focus on various constructs from positive psychology, with one such concept being hope. The concept of hope has been researched for decades and can be found throughout the literature, often described as a strength or an asset held by an individual. Hope has been associated with subjective wellbeing (Ciarrochi et al. 2015). There is no universal definition of hope; however, it could be considered “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant” (DuFault & Martocchio, 1985, p. 380). The most widely referenced model for understanding hope is Snyder’s (1994; 2000; 2002) Hope Theory, which identifies four components to hope: goals, pathway thinking, agency thinking, and barriers. Snyder’s theory may be unsuitable for caregivers of people living with dementia, for a number of reasons. Goal orientation can be a challenge due to the uncertainty of one’s future or not wanting to think about how the future may look. With respect to pathways, this thinking requires time and cognitive effort, which caregivers are often lacking due to caring responsibilities. Snyder’s process of agency thinking can lead to experiencing exhaustion, burnout, depression or grief.

There is little extant literature looking at hope within caregiving populations (Duggleby et al., 2012; Li & Loke, 2013; Walker et al., 2016), especially with those who care for people living with dementia. To date the only notable research exploring hope of caregivers of people living with dementia is that from Duggleby et al. (2009), who developed a grounded theory. The ‘renewing everyday hope’ theory identifies three sub-processes that contribute to the ‘renewing’ of an individual’s everyday hope: *coming to terms, finding the positives* and *seeing possibilities*. Coming to terms is about acknowledging and understanding the situation the carer is in and realising that they are doing the best they can for the person living with dementia. Coming to terms could also be viewed as when one achieves an acceptance of a given situation. Finding the positives is when one has come to terms and can consider and identify both the positive and negative aspects of caregiving, which one can then use to connect with other people. Seeing possibilities comes from one finding the positives, which enables one to see the possibilities and set short-term goals to aid in renewing one’s hope and provides a sense of control that can further renew everyday hope. While Duggleby et al.’s (2009) study and grounded theory identified the underlying processes of ‘renewing everyday hope’, *how* this process of renewing everyday hope can be supported or facilitated has yet to be investigated.

Aims and Rationale

Over 60% of people living with dementia are being cared for in the community by informal carers (Prince et al., 2014). This research, therefore, is focussed on developing support for informal caregivers.

The current study, to address gaps in the existing literature, aimed to explore the process of renewing hope in caregivers of people living with dementia to better understand how future interventions can support and facilitate the renewing of everyday hope for caregivers. Therefore, the following research question was developed: what are the views and experiences of carers of people living with dementia in the community on how renewing everyday hope can be supported?

At present, the available interventions offered to carers place little focus on facilitating or supporting experiences of hope, even when aiming to improve personal wellbeing (Walton et al., 2022). Existing works focus on stress, distress and burden in caregivers (Teahan et al., 2020). Duggleby et al.'s (2009) grounded theory and study demonstrated the value in a lived experience approach. The intention of this study is to develop a foundation rooted in the views and experiences of caregivers themselves, on which work can be done to enhance existing services to better support caregivers' renewal of hope.

Method

Design

The study took a qualitative, exploratory approach using semi-structured interview to explore the lived experiences of caregivers of people living with dementia. Demographic questionnaire data were gathered to contextualise the qualitative data, including caregiver and care recipient ages, sex, relationship of caregiver to care recipient, and dementia type.

Participants

Participants were sought by means of opportunistic sampling between January and May 2022 through social media platforms and from support groups locally accessed by caregivers in the north of England. Participants were invited to take part if they met the following criteria:

Inclusion criteria:

1. Self-reporting as being a current caregiver of a person living with dementia of any sub-type;
2. Person in receipt of support has a confirmed diagnosis of dementia;
3. Caregiving takes place in the community (i.e., within the home environment), since the study aimed to explore how experiences of hope could be enhanced or maintained, within the context of daily caregiving and given that the challenges of caregiving change when a person moves into residential care settings (Hainstock et al., 2017; Moore & Dow, 2015)
4. People aged over eighteen, since we were interested in adults holding caregiving roles;

5. Sufficient fluency in English to take part in an interview and;
6. Able to give informed consent.

Exclusion criteria:

1. Caregiving is exclusively provided by formal caregivers (i.e., a paid care service);
2. Person with dementia has died, due to the study being concerned with the views of current caregivers to people living with dementia;
3. Care recipient does not have a reported dementia diagnosis.

Procedure

Ethics

Ethical approval was granted by the Faculty of Health Sciences Research Ethics Committee at the University of Hull (REF: FHS336; Appendix D).

Anonymisation and pseudonymisation of all data was employed to ensure confidentiality was upheld throughout. Informed consent was obtained from participants by reading the information sheet (see Appendix E), asking any questions, and providing verbal consent to participation on the audio-video recording. The right to withdraw was emphasised prior to participation and no incentives were offered for participant involvement.

Data Collection

Participants who responded to adverts by contacting the researcher had interviews organised and held via videocall software, lasting between 43 and 57 minutes. The interview schedule (see Appendix F) acted as an aid to guide the structure of the interview, providing participants with broad questions to explore. The responses given by participants led the researcher to ask follow-up/clarification questions, meaning that participants ultimately directed discussions. The interview schedule was designed around targeting support that has been or is available to or utilised by participants, and support that could be made available or utilised, and was developed to target *what* and *how* elements of experiences. The interview schedule was developed with the aim of providing a basic structure for the interviews, while providing space and flexibility for participants to guide the interview session. Questions were formulated such that they would deconstruct the research question to facilitate participants answering it; questions subsequently explored one's views and experiences separately, as well as the *what* and *how* for both. The final sections of questions were developed with the aim of exploring how participants found discussing one's own views and experiences of hope, and encouraged reflection on how one's experiences of caregiving may have influenced said discussions. Although the interview was opened using a statement about Duggleby et al.'s (2009) theory, this was not intended to limit the scope of discussions, but to provide participants with context regarding why the research is being conducted.

Examples of follow-up questions include:

"Are there any services or provision, such as through the NHS or local authority that have supported your renewing of hope?"

"Can you tell me about how this made you feel?"

Each interview began with the researcher reading out an opening statement:

"Recent research suggests that hope is something that undergoes a daily process of renewal. In this interview I'd like to think about your experiences of hope, as well as your views on and experiences of this process of renewing everyday hope."

Data Analysis

Data from interviews was analysed using Braun and Clarke's (2006; 2022) reflexive Thematic Analysis (TA). The aim was to openly explore participants' views and experiences with regards to the process of renewing and sustaining hope. TA was an appropriate approach due to its flexible nature, which allows for inductive formation of themes across a data set. As the research was interested in understanding carer's experiences but not reflecting specifically on the meaning of those experiences to individuals, Interpretative Phenomenological Analysis (IPA) was deemed less applicable than TA. The present study was not intended to develop new theoretical understandings nor was it concerned with the specific role of language when constructing a reality, therefore grounded theory and discourse analysis approaches were not applicable. Due to the potential for content analysis to remove meaning from its context, and the numerical nature of its output, TA was deemed preferential to content analysis, despite commonalities in their process and intention. Narrative analysis was dismissed as it is a means of analysing how one's story is being told, rather than focussing on the content; this research was not concerned with how one's views and experiences were expressed but rather what those views and experiences are.

According to Terry and Hayfield (2021), six to ten participants should be sufficient for research using interviews and TA, therefore this study aimed to recruit to this figure. TA previously had ten participants (Braun & Clarke, 2013) as the ideal, however, recent literature suggests less focus should be placed on ‘dataset sizes’ and ‘saturation’ (Braun & Clarke, 2021; 2022). Braun and Clarke’s (2006; 2022) six phases of TA were followed (see Table 4), with an inductive approach being applied to the data. The participants’ own words were used from within the data to guide the generation of codes and themes. A researcher familiar with TA audited anonymised sections of transcripts, checking coding and derived themes, to minimise the primary researcher’s own biases influencing theme selection. Variations in identified themes were resolved through discussion and checking by a further independent researcher.

Table 4

Process of thematic analysis undertaken

Six phases	Procedure
1. Familiarisation of data	Audio-video recordings were transcribed. Transcripts were re-read multiples time and some initial observations were noted.
2. Generating initial codes	The data was systematically coded, using open coding. Codes were then collated.
3. Searching for themes	Patterns within the codes were identified and used to construct meaningful themes, which were constructed in relation to the research question.
4. Reviewing themes	Any subthemes were identified. Relationships between themes were reviewed, with some merged or divided as necessary, to reduce the

	number of themes and ensure they were concise, valued, and meaningful.
5. Defining themes	The essence of each theme was pulled out, and names were finalised for each theme and subtheme.
6. Writing up	The themes were written in such a manner to be both coherent and inclusive of the reference data, as appropriate.

Results

Five participants were recruited, demographic characteristics are outlined in Table 5. A further two people registered interest in the study; however, one was no longer caregiving as the person with dementia had died, and the other person declined the opportunity to participate despite their interest due to personal circumstances.

Table 5

Participant characteristics

Pseudonym	Sex	Ethnicity	Caregiver Age	Care Recipient Age	Relation to Care Recipient	Type of Dementia
Sarah	F	White British	23	84	Granddaughter	Mixed
Vivian	F	White British	46	79	Daughter	Parkinson's
Hilary	F	White British	51	84	Daughter	Alzheimer's
Amy	F	White British	52	86	Daughter	Alzheimer's
Adam	M	White British	45	78	Son	Alzheimer's

F, Female; M, Male

Thematic analysis generated five themes describing how caregivers' renewal of everyday hope can be supported. Two of the themes contained subthemes (see Table 6).

Table 6

Themes developed from analysis

Themes	Subthemes
Education	Availability of Information Appropriateness of Information
Practical Support	-
Accepting Circumstances and Adapting Goals	-
The Importance of Others' Support	Solidarity in Experience Recognition of the Burden of Responsibility
Focussing on Self	-

Theme: Education

This theme, which comprises two subthemes, relates to participants' expressed importance of information about dementia, its presentation and potential progression, and how caregivers can support those people living with dementia to live in a meaningful and dignified way despite the hardships faced because of the condition. Education is about caregivers being informed and being able to be realistic about their circumstances, meaning that caregivers' hope is grounded in reality.

Availability of Information

Participants emphasised information being readily available and easily accessible facilitates the gaining of knowledge they need to carry out their caregiving roles and having a sense of being well informed while doing so.

"we've also been given a lot of information, so that's really helped." (Amy)

Caregivers having to be proactive in seeking out information could leave them feeling unsupported by services, however, this may also encourage carers to act with agency to build their own knowledge. Developing knowledge independently can facilitate the acceptance of present and future circumstances, and aid with locating the positives in caregiving, which supports the renewing of hope.

"I think perhaps teaching, like, the skills needed. Like, I've had to learn everything. Everything I've learned about dementia, aside from the small module I did at uni, I've learned from researching and reading hundreds of forums" (Sarah)

One participant vocalised feeling that when information is honest and plentiful, great benefits can be reaped, but that this is needed for society too, not just caregivers.

"I think good information and more information and openness about dementia ... there's a weirdness in the way a lot of people understand or don't understand dementia still." (Hilary)

Appropriateness of Information

Some participants raised the importance of information being relevant to their experiences and appropriate for their specific circumstances, rather than general and limited to only the most common experiences. This is especially important for those caring for someone who has a rarer form of dementia;

"One thing I would say for me and my situation is that everything is very much geared up around dementia and memory loss ... not a great deal of knowledge from people I've worked with, who have come in to see dad, about Parkinson's dementia and the differences." (Vivian)

Ensuring information shared with caregivers is likely to be reflective of what they experience, increases the likelihood of caregivers feeling hopeful, as they feel understood and are able to prepare for what may come in the future. Appropriate information enables a sense of readiness or preparedness for the future; this ability to plan gives a sense of control that enables hope to grow. This fits with the 'seeing possibilities' component of Duggleby et al.'s (2009) renewing everyday hope theory.

"the story they're sort of telling with all that information kind of matches our actual experiences and what we are seeing." (Amy)

Theme: Practical Support

Participants recognised the importance of practical assistance in caring for someone with dementia, and how valuable this can be for caregivers; freeing up their time to focus on other aspects of care for the person living with dementia, or to focus on themselves. Practical support reduces the burden of responsibility on caregivers, creating space for hope to be renewed. From helping with laundry to sitting with someone with dementia to enable a caregiver time to engage in other activities;

"people around me are really important and what they offer, so again, that really good quality help and assistance with the practical tasks of being a carer is really important." (Vivian)

"My mother-in-law is incredibly supportive, she's very practical. People forget that with Alzheimer's and dementia, that maybe just doing, I don't know, my mum's washing for a week. You know that kind of thing is incredibly helpful." (Hilary)

Theme: Accepting Circumstances and Adapting Goals

Participants spoke about the role goal setting plays in hope; needing to have a sense of achievement to renew hope. Hilary explained that adaptation is an important part of fostering hope in caregiving and encouraging hope to grow and renew daily. Adapting one's goals to better fit with everchanging circumstances facilitates the achievement of said goals, as the adaptations make it easier to succeed, and thus feel more hopeful.

"I've learned that you can learn to take joy and pleasure in very small things, and adjust your kind of hope goals, into the future. I hope for little things rather than big things with dementia" (Hilary)

Participants outlined the simplest way to adapt is to adjust the size of one's goals, making them more manageable and increasing the likelihood of their success. Ensuring goals are realistic and within reach;

"I think it's realistic when you keep things small ... the degree of hope probably matches how realistic something is" (Amy)

Part of adapting within the process of renewing hope is accepting the given situation and what the future may hold, without losing a sense of positivity about what can be achieved. This acceptance, or coming to terms, is the first key step in Duggleby et al.'s (2009) model, and enables the rest of the process (finding the positives and seeing possibilities) to take place.

"For me, acceptance doesn't mean that hope is then extinguished, it's just that my hope goes onto a different track ... in order to function and be happy you have to, you have to change yourself as well as the situation, because otherwise the situation just controls you." (Hilary)

Theme: The Importance of Others' Support

This theme comprises two subthemes, which relate to how other people are able to use the sharing of stories and demonstration of admiration to improve a caregiver's sense of worth and validate their experiences as normal. The importance of other's support is about caregivers not being able to do it alone and needing those around them to assist both in aspects of caregiving and the process of renewing everyday hope.

Solidarity in Experience

When discussing hope, participants referred to feeling like others' having similar experiences to their own helps caregivers not to feel alone or isolated and provides evidence that positivity does exist when caring for someone living with dementia. Hearing other people's stories facilitates caregivers in 'finding the positives' (Duggleby et al., 2009); having a sense of caregiving in dementia being a positive experience allows carers to continue finding the positive aspects and focus on them, feeding the process of renewing hope. Connectedness with other caregivers and validation of experiences are important too.

"Perhaps going to a carers meeting, and then the next person to me going 'oh yeah, that same thing happened to me but then this happened and that gave me lots of hope' would remind me that hope is up and down for other people … So, perhaps platforms where you can make it clear that everyone's life isn't the perfect little sunshine and roses, they make it look like, and that not everyone gets the hope or the full extent of the hope, would benefit me." (Sarah)

Participants shared in discussions about a gaining a sense from other people's experiences that hope is not a constant, but instead something that can be up and down. This may ease pressure on caregivers to feel hopeful all the time, as they accept that such a notion is unrealistic. Accepting the fluidity of hope enables the renewal process to be facilitated.

"So, I think having an outside lens looking at what people do around you and other people's stories can often help you to feel hopeful I think because you know you're not perhaps the only one that's struggling" (Vivian)

Recognition of the Burden of Responsibility

People who do not provide care are frequently noted as saying to caregivers *'I don't know how you do it'*, acknowledging the significant burden of responsibility placed on the shoulders of caregivers. Some participants expressed feeling unseen, unheard, and often forgotten about. Recognition of the level of responsibility held by caregivers and the respect gained for the challenges caregivers undertake is important and empowering.

"I think, through them feeling more like they are existing in the world rather than feeling they exist in the dark … there is something really powerful in being recognised and being recognised for doing something good" (Hilary)

Theme: Focussing on Self

Participants described how a key component in being able to remain hopeful and renew hope daily, is ensuring they take care of themselves whilst caring for someone with dementia. Accepting that while they are doing all they can to care for a loved one, they must also care for themselves in order to keep going. At the centre of focussing on oneself was the idea of a caregiver's identity; that although they are a carer, they are still so much more than "just a carer" (Vivian);

"I think just that feeling part of a community that I mentioned, just makes me feel like I'm not just a mum, not just a carer and not just a daughter, I am something for myself really. A bit more individual." (Vivian)

"Getting information about looking after yourself is sort of, I don't know if it's hope, but it's giving you permission to look after yourself." (Amy)

In discussions about hope, participants made reference to the need for achieving a balance between renewing everyday hope and enduring negative aspects of caregiving.

"And knowing that even with bad things in your life, you can still be happy and still be hopeful. And remembering to carry on with other stuff as well, you know, to carry on being yourself and not just being subsumed into carer mode" (Hilary)

Discussion

Overview of Findings

The number of people living with a diagnosis of dementia is increasing, therefore, the number of people providing care for them is also rising. As far as the researchers are aware, this is the first study to explore carers' views and experiences on how the process of renewing everyday hope can be supported in relation to dementia. This research aimed to identify what could be done to aid with facilitating and maintaining the renewal of everyday hope, with a view to developing future support.

The findings suggest that in order to support caregivers to maintain hope fully we need to provide better access to information tailored to circumstances (e.g., about specific diagnoses), a sense of being recognised and acknowledged for caregiving responsibilities and space to have agency and express aspects of one's identity that are not related to caregiving. These areas have been identified within a small group of caregivers as potentially important in the process of renewing everyday hope, however, cannot be said to be key to all caregivers. Further understanding of specific factors that help renew and sustain hope is still required. Drawn from carers' experiences, changes that may be needed to enable support in renewing hope could target how organisations currently operate with regards to caregiver support, as well as targeting societal attitudes and beliefs about those who care for persons living with dementia.

This paper previously described potential challenges that may be faced by caregivers of people living with dementia with respect to Snyder's Hope Theory. Goals are outlined as components of Snyder's theory as well as Duggleby's grounded theory of renewing everyday hope; therefore, the presented findings may be congruent with both theories, at least partially. The identification and achievability of goals was noted to be of considerable significance to those interviewed. The extrapolation of themes from this study and comparison with established theories should be done with caution due to the limited sample collected, which may have made the drawing out of reliable and accurate patterns difficult, if at all possible (Braun & Clarke, 2013).

The areas identified as helpful in supporting caregiver's hope renewal fit with the findings of Wolverson et al. (2010), who found that people living with dementia believed hope to be a sense of energy, involving support from others and involving a context of uncertainty. Similarities between caregiver and care recipient experiences of hope could suggest that future targeted support for renewing hope can be applied in similar ways to both persons living with dementia and their caregivers.

Clinical Implications and Research

This research highlights the importance of services needing to support caregivers' timely access to information about dementia and caregiving, particularly for those with rarer forms of dementia. This information helps people to be realistic about the future and make plans accordingly (Moore et al., 2020). A realistic view and understanding of the future, particularly in caregiving for someone living with dementia, is important for coming to terms with changes in relationships and ultimate progression of the dementia. Dementia is a progressive life-limiting condition, therefore, ensuring people understand the possible progression of their loved one's dementia will allow them to accept the future endpoint and changes their focus toward looking for the positives within caregiving. Having the necessary information to make plans can give people a sense of control, which can be important within the process of renewing hope.

The value caregiver's see in setting realistic goals and re-defining goals as the caregiving situation changes is important. The setting and re-defining of goals may be areas that caregiver's require support in from services. We know that goal setting supports hope in people with chronic illness (Wolverson et al., 2010). Clinicians can support caregivers with identifying broad goals, breaking them down into smaller more manageable targets that are realistic, identifying and developing strategies for overcoming obstacles (Dionne-Odom et al., 2019) and developing means for evaluating if goals have been achieved successfully. Ensuring goal setting is collaborative (Wagner et al., 2005) and caregiver-led will facilitate a sense of agency.

The role of others in supporting caregivers' hope was another crucial component of renewing everyday hope identified in this study. Solidarity and recognition were the two key concepts drawn out in relation to others supporting hope. Solidarity being a sense of togetherness and connectedness with the caregiving community; that people are not in this journey alone and other people have similar experiences in their caregiving. While recognition is about having one's caregiving contributions noticed and appreciated, given the significant hardships faced and sacrifices made to provide care for a loved one. Both concepts can be supported through peer support (Carter et al., 2020), such as local support groups, therefore services should continue to encourage caregivers to attend. It may also be the responsibility of services to identify and tackle potential obstacles that may be in the way of caregivers freely accessing peer support groups. For example, facilitating both in-person and online engagement in groups, which has become particularly important in recent years due to the Covid-19 pandemic. There may also be a need for specific relationship-centred interventions from clinicians, that involve whole families, not just persons living with dementia and their primary/most active caregiver. Such interventions could address that dementia diagnoses are given to systems not just individuals and facilitate a sharing of the burden of responsibility outside of just the primary caregiver.

Admiral nurses are specialist dementia nurses introduced by Dementia UK to provide support to families of people living with dementia using a biopsychosocial approach to care (Aldridge & Harrison Dening, 2019), and fit into the third tier of the Three-Tiered ABC Model (Aldridge et al., 2020). The work carried out by Admiral Nurses was commended by participants within this research, which is understandable as their approach to care and portfolio of expertise includes much of what this study has identified (National Health Service, 2016) as important in the renewal of everyday hope. Therefore, greater opportunities should be made for caregivers and their families to access Admiral Nurses, and the outcomes for these services in relation to caregiver hope may be worthwhile.

This research was established as an exploratory study, aiming to start developing an understanding rooted in the voices of caregivers. Building on the findings of this study and its limitations, further research is needed in the following areas:

- Research to examine experiences of hope in families engaging with Admiral Nurses, developing an understanding of what in their care approach underpins the renewing of hope for caregivers.

- An exploration of the views and experiences of supporting hope in caregivers of people living with rare dementias (e.g., Parkinson's dementia, Lewy bodies, frontotemporal).
- Develop an understanding of how to support hope in caregivers of younger people living with dementia, and how this may be similar or different to caring for an older person with dementia.
- Exploring views on how to support the renewing of hope in younger caregivers of people living with dementia, considering why younger carers may require different forms of support to their older counterparts.

Continuing from the current study, a larger scale replication to seek support or validation for the identified themes may be beneficial and would assist with supporting a move to the next stage of developing targeted hope interventions for caregivers. This may also include research exploring the state of established services from the public and charitable sectors aimed at caregivers. Walton et al.'s (2022) review identified the need for positive psychology interventions for caregivers, including the benefits of a hope-based therapy programme.

Limitations

The presented study represents the voices of a limited sample of five participants. This study advertised on three social media platforms (Twitter, Facebook, LinkedIn), a regional BBC radio show interview, in a university staff bulletin, and by contacting more than a dozen local carer and dementia support groups and charitable organisations. Recruitment for this research proved to be challenging, due to the changes made to carers lives by Covid-19. People living with dementia and their caregivers have been particularly affected by the pandemic, resulting in great strain on caregivers (Alzheimer’s Society, 2020) and reduced availability for participating in dementia-related research.

Braun and Clarke (2013) would suggest that the size of this study’s sample is insufficient. This is because they argue that irrespective of interview length or detail, only five interviews would hinder the thematic analysis process, which is focussed on the identification of patterns across data. Without a large dataset, this may be difficult to achieve effectively.

This study’s sample were a fairly homogenous group; there is little diversity on the basis of sex, age, relation to person living with dementia, and the type of dementia. Statistics suggest that 60-70% of diagnosed dementias are Alzheimer’s disease (Office for Health Improvement and Disparities, 2022), therefore it would not be surprising for most participants to care for a person living with Alzheimer’s. However, the presented study’s participants do not accurately reflect the prevalence of other dementia diagnoses; meaning the voices of those caregivers are missing.

Conclusion

This study’s findings indicate that agency, grounding in reality through the provision of information, and recognition of caregiving contributions are important components to focus on for supporting the renewal of everyday hope in caregivers of people living with dementia. The implications of these findings are that clinician’s need to provide support to caregivers to aid with setting and re-defining goals in a long-term model of care which recognises how carers adapt and adjust overtime.

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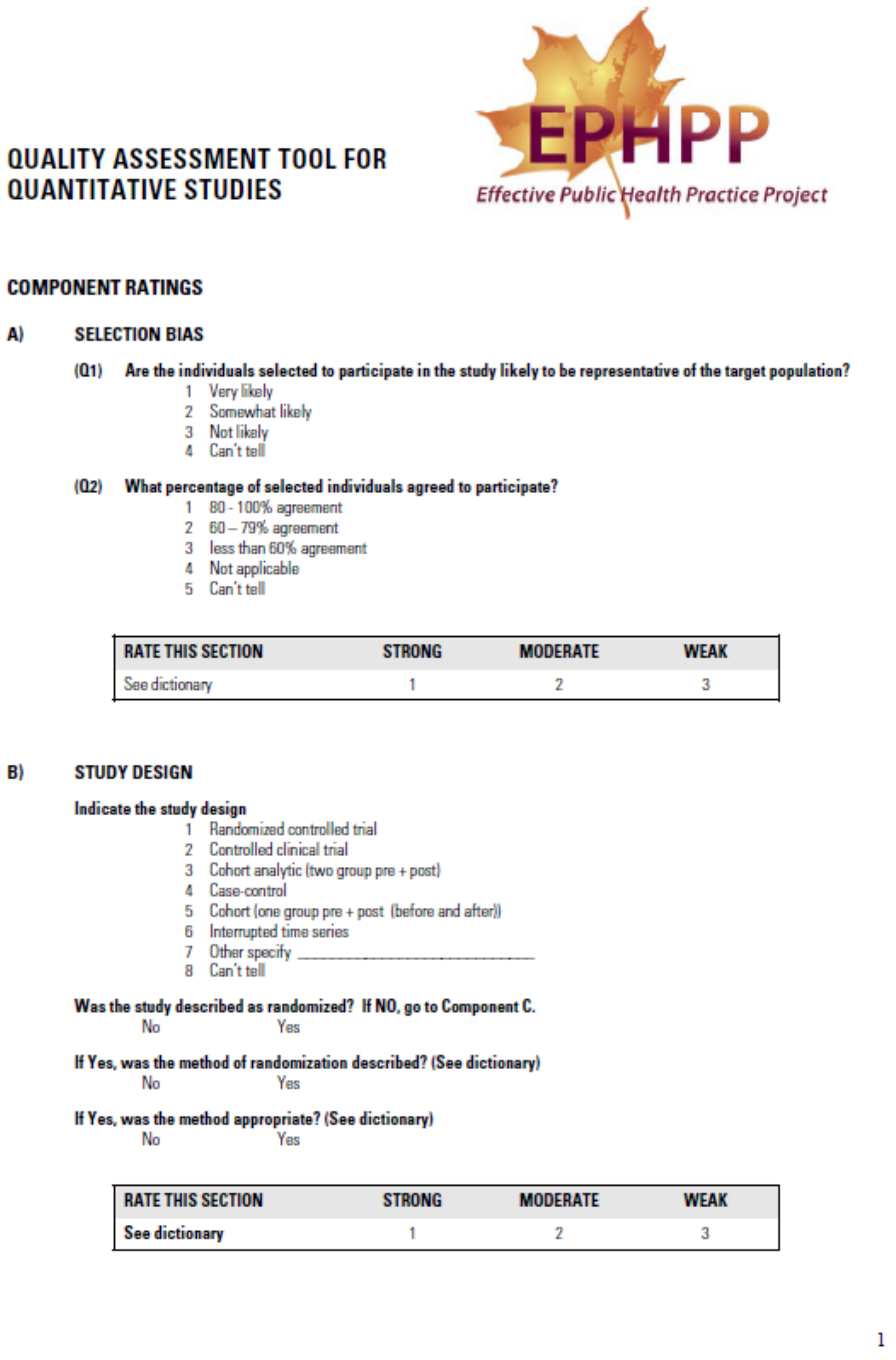
Part Three: Appendices

Appendix A: Quality Checklist Criteria Applied to Studies



EPHPP
Effective Public Health Practice Project

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?
1 Very likely
2 Somewhat likely
3 Not likely
4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?
1 80 - 100% agreement
2 60 – 79% agreement
3 less than 60% agreement
4 Not applicable
5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design
1 Randomized controlled trial
2 Controlled clinical trial
3 Cohort analytic (two group pre + post)
4 Case-control
5 Cohort (one group pre + post (before and after))
6 Interrupted time series
7 Other specify ______________________________
8 Can't tell

Was the study described as randomized? If NO, go to Component C.
No Yes

If Yes, was the method of randomization described? (See dictionary)
No Yes

If Yes, was the method appropriate? (See dictionary)
No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1 Yes
2 No
3 Can't tell

The following are examples of confounders:

1 Race
2 Sex
3 Marital status/family
4 Age
5 SES (income or class)
6 Education
7 Health status
8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1 80 – 100% (most)
2 60 – 79% (some)
3 Less than 60% (few or none)
4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1 Yes
2 No
3 Can't tell

(Q2) Were the study participants aware of the research question?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1 Yes
2 No
3 Can't tell

(Q2) Were data collection tools shown to be reliable?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1 Yes
2 No
3 Can't tell
4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell
5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell

(Q2) Was the consistency of the intervention measured?

1 Yes
2 No
3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

4 Yes
5 No
6 Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

1 Yes
2 No
3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1 Yes
2 No
3 Can't tell

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	**SELECTION BIAS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
B	**STUDY DESIGN**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
C	**CONFOUNDERS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
D	**BLINDING**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
E	**DATA COLLECTION METHOD**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
F	**WITHDRAWALS AND DROPOUTS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1	STRONG	(no WEAK ratings)
2	MODERATE	(one WEAK rating)
3	WEAK	(two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

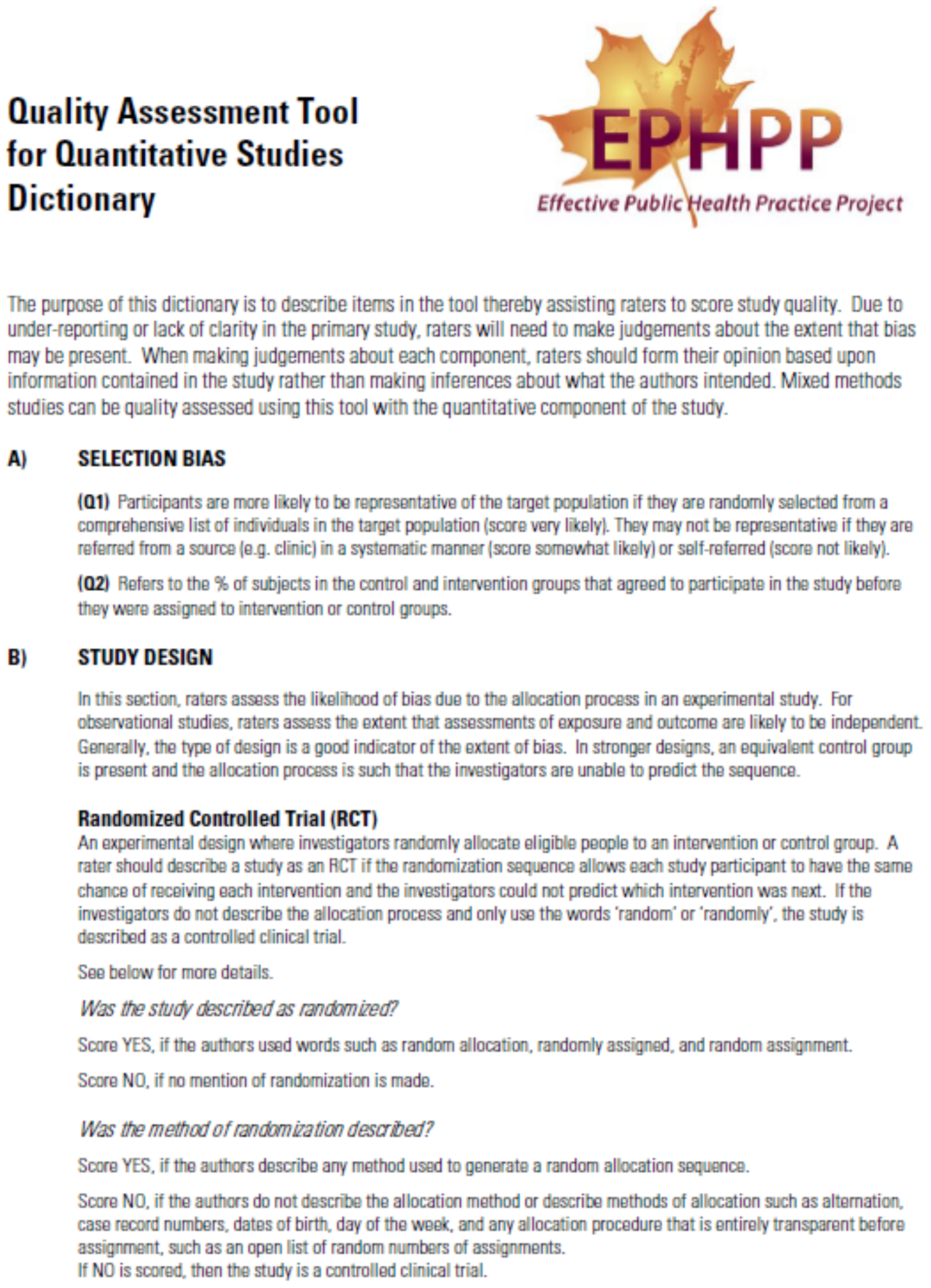
If yes, indicate the reason for the discrepancy

1 Oversight
2 Differences in interpretation of criteria
3 Differences in interpretation of study

Final decision of both reviewers (circle one):

1 STRONG
2 MODERATE
3 WEAK

Appendix B: Quality assessment tool domains meanings and scoring guidance



Quality Assessment Tool for Quantitative Studies Dictionary

EPHPP
Effective Public Health Practice Project

The purpose of this dictionary is to describe items in the tool thereby assisting raters to score study quality. Due to under-reporting or lack of clarity in the primary study, raters will need to make judgements about the extent that bias may be present. When making judgements about each component, raters should form their opinion based upon information contained in the study rather than making inferences about what the authors intended. Mixed methods studies can be quality assessed using this tool with the quantitative component of the study.

A) SELECTION BIAS

(Q1) Participants are more likely to be representative of the target population if they are randomly selected from a comprehensive list of individuals in the target population (score very likely). They may not be representative if they are referred from a source (e.g. clinic) in a systematic manner (score somewhat likely) or self-referred (score not likely).

(Q2) Refers to the % of subjects in the control and intervention groups that agreed to participate in the study before they were assigned to intervention or control groups.

B) STUDY DESIGN

In this section, raters assess the likelihood of bias due to the allocation process in an experimental study. For observational studies, raters assess the extent that assessments of exposure and outcome are likely to be independent. Generally, the type of design is a good indicator of the extent of bias. In stronger designs, an equivalent control group is present and the allocation process is such that the investigators are unable to predict the sequence.

Randomized Controlled Trial (RCT)
An experimental design where investigators randomly allocate eligible people to an intervention or control group. A rater should describe a study as an RCT if the randomization sequence allows each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. If the investigators do not describe the allocation process and only use the words 'random' or 'randomly', the study is described as a controlled clinical trial.

See below for more details.

Was the study described as randomized?

Score YES, if the authors used words such as random allocation, randomly assigned, and random assignment.

Score NO, if no mention of randomization is made.

Was the method of randomization described?

Score YES, if the authors describe any method used to generate a random allocation sequence.

Score NO, if the authors do not describe the allocation method or describe methods of allocation such as alternation, case record numbers, dates of birth, day of the week, and any allocation procedure that is entirely transparent before assignment, such as an open list of random numbers of assignments.
If NO is scored, then the study is a controlled clinical trial.

Was the method appropriate?

Score YES, if the randomization sequence allowed each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. Examples of appropriate approaches include assignment of subjects by a central office unaware of subject characteristics, or sequentially numbered, sealed, opaque envelopes.

Score NO, if the randomization sequence is open to the individuals responsible for recruiting and allocating participants or providing the intervention, since those individuals can influence the allocation process, either knowingly or unknowingly.

If NO is scored, then the study is a controlled clinical trial.

Controlled Clinical Trial (CCT)
An experimental study design where the method of allocating study subjects to intervention or control groups is open to individuals responsible for recruiting subjects or providing the intervention. The method of allocation is transparent before assignment, e.g. an open list of random numbers or allocation by date of birth, etc.

Cohort analytic (two group pre and post)
An observational study design where groups are assembled according to whether or not exposure to the intervention has occurred. Exposure to the intervention is not under the control of the investigators. Study groups might be non-equivalent or not comparable on some feature that affects outcome.

Case control study
A retrospective study design where the investigators gather 'cases' of people who already have the outcome of interest and 'controls' who do not. Both groups are then questioned or their records examined about whether they received the intervention exposure of interest.

Cohort (one group pre + post (before and after)
The same group is pretested, given an intervention, and tested immediately after the intervention. The intervention group, by means of the pretest, act as their own control group.

Interrupted time series
A time series consists of multiple observations over time. Observations can be on the same units (e.g. individuals over time) or on different but similar units (e.g. student achievement scores for particular grade and school). Interrupted time series analysis requires knowing the specific point in the series when an intervention occurred.

Other:
One time surveys or interviews

C) CONFOUNDERS

By definition, a confounder is a variable that is associated with the intervention or exposure and causally related to the outcome of interest. Even in a robust study design, groups may not be balanced with respect to important variables prior to the intervention. The authors should indicate if confounders were controlled in the design (by stratification or matching) or in the analysis. If the allocation to intervention and control groups is randomized, the authors must report that the groups were balanced at baseline with respect to confounders (either in the text or a table).

D) BLINDING

(Q1) Assessors should be described as blinded to which participants were in the control and intervention groups. The purpose of blinding the outcome assessors (who might also be the care providers) is to protect against detection bias.

(Q2) Study participants should not be aware of (i.e. blinded to) the research question. The purpose of blinding the participants is to protect against reporting bias.

E) DATA COLLECTION METHODS

Tools for primary outcome measures must be described as reliable and valid. If 'face' validity or 'content' validity has been demonstrated, this is acceptable. Some sources from which data may be collected are described below:

<u>Self reported data</u> includes data that is collected from participants in the study (e.g. completing a questionnaire, survey, answering questions during an interview, etc.).

<u>Assessment/Screening</u> includes objective data that is retrieved by the researchers. (e.g. observations by investigators).

<u>Medical Records/Vital Statistics</u> refers to the types of formal records used for the extraction of the data.

Reliability and validity can be reported in the study or in a separate study. For example, some standard assessment tools have known reliability and validity.

F) WITHDRAWALS AND DROP-OUTS

Score **YES** if the authors describe BOTH the numbers and reasons for withdrawals and drop-outs.

Score **NO** if either the numbers or reasons for withdrawals and drop-outs are not reported.

Score **NOT APPLICABLE** if the study was a one-time interview or survey where there was not follow-up data reported.

The percentage of participants completing the study refers to the % of subjects remaining in the study at the final data collection period in all groups (i.e. control and intervention groups).

G) INTERVENTION INTEGRITY

The number of participants receiving the intended intervention should be noted (consider both frequency and intensity). For example, the authors may have reported that at least 80 percent of the participants received the complete intervention. The authors should describe a method of measuring if the intervention was provided to all participants the same way. As well, the authors should indicate if subjects received an unintended intervention that may have influenced the outcomes. For example, co-intervention occurs when the study group receives an additional intervention (other than that intended). In this case, it is possible that the effect of the intervention may be over-estimated. Contamination refers to situations where the control group accidentally receives the study intervention. This could result in an under-estimation of the impact of the intervention.

H) ANALYSIS APPROPRIATE TO QUESTION

Was the quantitative analysis appropriate to the research question being asked?

An intention-to-treat analysis is one in which all the participants in a trial are analyzed according to the intervention to which they were allocated, whether they received it or not. Intention-to-treat analyses are favoured in assessments of effectiveness as they mirror the noncompliance and treatment changes that are likely to occur when the intervention is used in practice, and because of the risk of attrition bias when participants are excluded from the analysis.

Component Ratings of Study:

For each of the six components A – F, use the following descriptions as a roadmap.

A) SELECTION BIAS

Strong: The selected individuals are very likely to be representative of the target population (Q1 is 1) **and** there is greater than 80% participation (Q2 is 1).

Moderate: The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); **and** there is 60 - 79% participation (Q2 is 2). 'Moderate' may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can't tell).

Weak: The selected individuals are not likely to be representative of the target population (Q1 is 3); **or** there is less than 60% participation (Q2 is 3) **or** selection is not described (Q1 is 4); and the level of participation is not described (Q2 is 5).

B) DESIGN

Strong: will be assigned to those articles that described RCTs and CCTs.

Moderate: will be assigned to those that described a cohort analytic study, a case control study, a cohort design, or an interrupted time series.

Weak: will be assigned to those that used any other method or did not state the method used.

C) CONFOUNDERS

Strong: will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); **or** (Q2 is 1).

Moderate: will be given to those studies that controlled for 60 – 79% of relevant confounders (Q1 is 1) **and** (Q2 is 2).

Weak: will be assigned when less than 60% of relevant confounders were controlled (Q1 is 1) **and** (Q2 is 3) **or** control of confounders was not described (Q1 is 3) **and** (Q2 is 4).

D) BLINDING

Strong: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **and t**he study participants are not aware of the research question (Q2 is 2).

Moderate: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **or** the study participants are not aware of the research question (Q2 is 2).

Weak: The outcome assessor is aware of the intervention status of participants (Q1 is 1); **and** the study participants are aware of the research question (Q2 is 1); **or b**linding is not described (Q1 is 3 and Q2 is 3).

E) DATA COLLECTION METHODS

Strong: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have been shown to be reliable (Q2 is 1).

Moderate: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have not been shown to be reliable (Q2 is 2) **or** reliability is not described (Q2 is 3).

Weak: The data collection tools have not been shown to be valid (Q1 is 2) **or** both reliability and validity are not described (Q1 is 3 and Q2 is 3).

F) WITHDRAWALS AND DROP-OUTS - a rating of:

Strong: will be assigned when the follow-up rate is 80% or greater (Q1 is 1 and Q2 is 1).

Moderate: will be assigned when the follow-up rate is 60 – 79% (Q2 is 2) **OR** Q1 is 4 or Q2 is 5.

Weak: will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q1 is No or Q2 is 4).

Not Applicable: if Q1 is 4 or Q2 is 5.

Appendix C: Quality ratings awarded to each study included in the review

Paper Author & Year	Criteria ‘A’	Criteria ‘B’	Criteria ‘C’	Criteria ‘D’	Criteria ‘E’	Criteria ‘F’	Global Rating
Azimian et al. (2011)	Strong	Strong	Weak	Weak	Strong	Strong	Weak
Barog et al. (2015)	Moderate	Moderate	Strong	Weak	Strong	Strong	Moderate
Bartfay & Bartfay (2013)	Moderate	Moderate	Strong	Weak	Strong	Moderate	Moderate
Cheng et al. (2019)	Strong	Strong	Weak	Strong	Strong	Strong	Moderate
Cheng et al. (2020)	Strong	Strong	Weak	Strong	Strong	Strong	Moderate
Fu et al. (2020)	Strong	Strong	Strong	Weak	Strong	Strong	Moderate
Gallagher et al. (2020)	Strong	Strong	Strong	Strong	Strong	Weak	Moderate
Meichsner et al. (2019)	Strong	Moderate	Strong	Weak	Strong	Strong	Moderate
Mowla et al. (2020)	Moderate	Moderate	Strong	Weak	Strong	Moderate	Moderate
Norouzi et al. (2014)	Strong	Moderate	Weak	Weak	Strong	Strong	Weak
van der Heide et al. (2021)	Strong	Strong	Strong	Moderate	Moderate	Strong	Strong

Appendix D: Ethical Approval

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Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 463336 | E: e.walker@hull.ac.uk
w: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL
Alexander Walton
Faculty of Health Sciences
University of Hull
Via email

4th October 2021

Dear Alexander

REF FHS336 - Enhancing Experiences of Hope in Caregivers of People Living with Dementia

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

UNIVERSITY
OF HULL

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Appendix E: Participant Information Sheet

Information about the research

Enhancing Experiences of Hope in Caregivers of People Living with Dementia

You are being invited to take part in a research study, which is trying to learn something about the experience of hope for carers of people who are living with dementia.

Before you decide whether or not to take part, you need to understand why the research is being done and what taking part would involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask if there is anything that is not clear or if you would like more information.

Thank you for taking the time to read this information.

What is the purpose of the study?

This study is looking to understand more about the experience of hope for carers of people who are living with dementia. We know that people's hopes change as they go through life and have different experiences, and that the things we hope for can vary from person to person, day-to-day. This study wants to explore; what hope means to carers of people with dementia, what can be done to support the hope of carers and how this support will maintain their hope.

Why have I been invited to take part?

You are being invited to participate in this study because you identify as being a carer of a person living with dementia, who is cared for in the community, and that you are able to speak English.

Do I have to take part?

No, the study is voluntary. If you decide to take part you will be asked to sign a form to show that you have agreed to take part in this research. You will be free to withdraw before data analysis begins, without giving a reason.

What will happen if I take part?

If you agree to take part, then you will be contacted to arrange a convenient date and time for the interview. Interviews may take place in person, however, they are more likely to be held online. They will involve talking about your views and experiences. The interview will be conducted by a trainee clinical psychologist called Alexander who is conducting this research as part of his doctorate. The conversation will be audio/video taped, with your consent. There are no 'correct' or 'incorrect' answers to any of the questions, as we want to hear your personal views and opinions. Interviews will last for 45-60 minutes but we can take breaks and fit around you and the person you are caring for. As part of participation you will also be asked to provide basic personal information, such as age, sex and your relationship to the person living with dementia, which will help to give background to your views and experiences.

What are the possible risks of taking part?

The questions we want to ask will require you to think about your experiences of hope in caring for a person living with dementia, and how future hope can be maintained or improved. If you feel this will be too upsetting or uncomfortable you do not have to take part. If at any point during the interview, or following the interview, you feel uncomfortable in any way, you can withdraw from the study. We will give everyone a list of places you can go for support.

What are the possible benefits of taking part?

We cannot promise that this study will help you, although research has found that people can find talking about their hopes to be beneficial. It is hoped that the information we get from this study will help improve the understanding of the needs of carers and contribute to better ways of supporting carers of persons living with dementia.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR).

All data collected will be stored in password protected files on an encrypted laptop during the study, and then anonymised data will be held as MS Word documents on secure drives for 10 years in the research supervisor's locked cabinets at the University of Hull. Any audio/video recordings will be destroyed after use. All data will be kept strictly confidential, and any identifying information, such as names, will be deleted from interviews so that you cannot be identified.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you. Information about how the University of Hull processes your data can be found at https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Hull Data Protection Officer [dataprotection@hull.ac.uk]. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk

What if I change my mind about taking part?

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study up until September 2021, after which withdrawal of your data will no longer be possible due to the data being anonymised and combined with data from other participants. If you choose to withdraw from the study, prior to the start of data analysis, we will not retain the information you have given thus far.

What will happen to the results of the study?

The results of the study will be summarised in a thesis, which will be submitted for publication in an academic journal. No details will be included in the write up that could be used to identify individual participants.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by the Faculty of Health Sciences Ethics Committee, University of Hull.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Alexander Walton (Chief Investigator)
Trainee Clinical Psychologist
Tel: 01482 464170
Add: Department of Psychological Health, Wellbeing and Social Work
Aire Building
University of Hull
Cottingham Road
Hull
HU6 7RX

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

Dr Emma Wolverson
Tel: 01482 464170
Add: Department of Psychological Health, Wellbeing and Social Work
Dearne Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Alternatively please contact, coo@hull.ac.uk

If you have any queries please do not hesitate to contact me. Whether or not you decide to take part in this research project, I would like to thank you for taking time to read the information.

Yours Sincerely,

Alexander Walton

Appendix F: Interview Schedule

Opening statement:

Recent research suggests that hope is something that undergoes a daily process of renewal. In this interview I’d like to think about your experiences of hope, as well as your views on and experiences of this process of renewing everyday hope.

- Can you tell me about your experiences of hope since becoming a caregiver of a person living with dementia?
    - Prompt: Have your experiences of hope notably change or varied since taking on caring responsibilities?
- Can you tell me about *what*, in your experience, has supported/facilitated/maintained/enhanced your renewing of everyday hope?
    - Prompts: Any services through the NHS/local council/charitable organisations that have supported hope renewal? Any support received from family, friends, colleagues?
- Would you be able to tell me about *how*, in your experience, what you have described may have supported your process of renewing everyday hope?
    - Prompts: Tell me about how this made you feel? What did you gain from these? Did you gain a greater sense of connectedness?
- Can you tell me about *what*, in your opinion, may be able to support/facilitate/maintain/enhance your renewing of everyday hope?
    - Prompt: Is there anything local services/provisions could offer that may help?
- Would you be able to tell me about *how*, in your opinion, what you have described may have support your process of renewing everyday hope?
- How do you think your experiences of caregiving may have influenced our conversation about hope today?
- How have you found discussing hope and how your hope has been or may be supported?

- Prompts: Is there anything you have struggled with discussing? Have you found any aspect of today’s conversation interesting or insightful?

Appendix G: Guidelines for submission to International Journal of Applied Positive Psychology applied to the Systematic Literature Review

Instructions for Authors

Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Online Submission

Please follow the hyperlink “Submit manuscript” and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Article types

- Research paper – average length approximately 7,500 words including references. Articles should be no shorter than 5,000 words and no longer that 10,000 words.

- Review article – average length approximately 10,000-12,500 words including references.
- Brief reports of null findings, replications, sensitivity testing or method variance – This format focuses on publishing null findings, replications, or analyses testing the effects of applying different methods or samples (sensitivity testing and method effects). Note the latter can be re-analyses of previously published papers. Typical length maximum 500 words introduction, 500 word discussion, 2500 word method and results sections (not including tables and figures). No supplementary materials sections.

Title Page

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Abstract

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references.

For life science journals only (when applicable)

- Trial registration number and date of registration for prospectively registered trials
- Trial registration number and date of registration, followed by “retrospectively registered”, for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- **Competing Interests:** Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Manuscripts with mathematical content can also be submitted in LaTeX. We recommend using Springer Nature’s LaTeX template.

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author's name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g. "https://doi.org/abc").

- Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture, 8*(3), 207–217. https://doi.org/10.1037/ppm0000185
- Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. https://doi.org/10.1097/PHM.0000000000001435
- Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.
- Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.
- Online document Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view

Tables

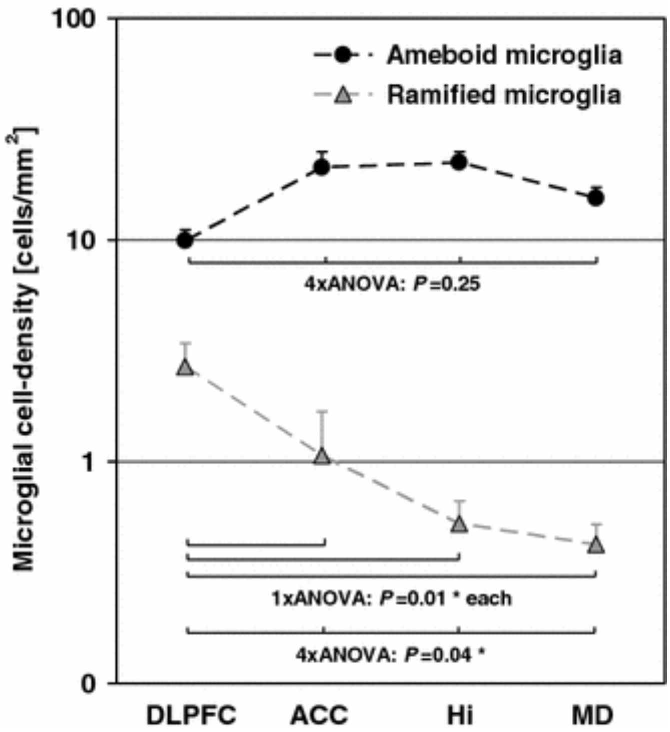
- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Artwork and Illustrations Guidelines

Electronic Figure Submission

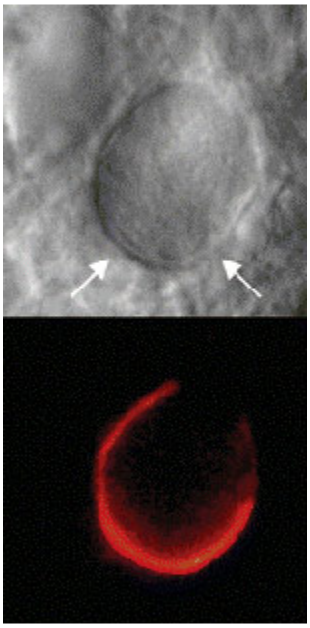
- Supply all figures electronically.
- Indicate what graphics program was used to create the artwork.
- For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.
- Vector graphics containing fonts must have the fonts embedded in the files.
- Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

Line Art



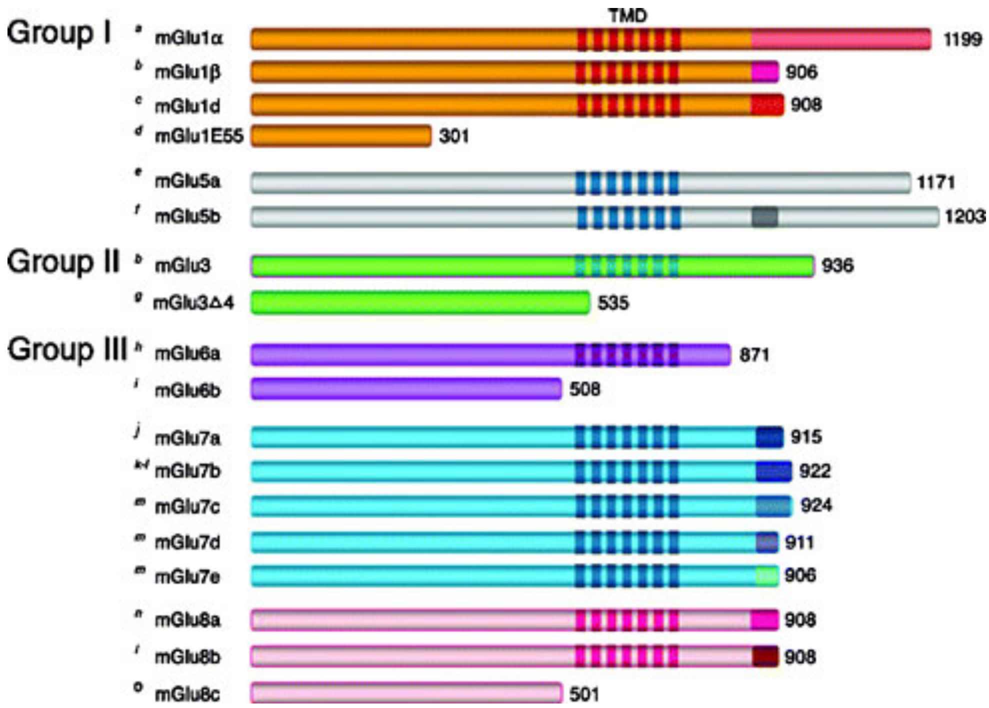
- Definition: Black and white graphic with no shading.
- Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.
- All lines should be at least 0.1 mm (0.3 pt) wide.
- Scanned line drawings and line drawings in bitmap format should have a minimum resolution of 1200 dpi.
- Vector graphics containing fonts must have the fonts embedded in the files.

Halftone Art



- Definition: Photographs, drawings, or paintings with fine shading, etc.
- If any magnification is used in the photographs, indicate this by using scale bars within the figures themselves.
- Halftones should have a minimum resolution of 300 dpi.

Combination Art



- Definition: a combination of halftone and line art, e.g., halftones containing line drawing, extensive lettering, color diagrams, etc.
- Combination artwork should have a minimum resolution of 600 dpi.

Color Art

- Color art is free of charge for online publication.
- If black and white will be shown in the print version, make sure that the main information will still be visible. Many colors are not distinguishable from one another when converted to black and white. A simple way to check this is to make a xerographic copy to see if the necessary distinctions between the different colors are still apparent.
- If the figures will be printed in black and white, do not refer to color in the captions.
- Color illustrations should be submitted as RGB (8 bits per channel).

Figure Lettering

- To add lettering, it is best to use Helvetica or Arial (sans serif fonts).
- Keep lettering consistently sized throughout your final-sized artwork, usually about 2–3 mm (8–12 pt).
- Variance of type size within an illustration should be minimal, e.g., do not use 8-pt type on an axis and 20-pt type for the axis label.
- Avoid effects such as shading, outline letters, etc.
- Do not include titles or captions within your illustrations.

Figure Numbering

- All figures are to be numbered using Arabic numerals.
- Figures should always be cited in text in consecutive numerical order.
- Figure parts should be denoted by lowercase letters (a, b, c, etc.).
- If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures,"A1, A2, A3, etc." Figures in online appendices [Supplementary Information (SI)] should, however, be numbered separately.

Figure Captions

- Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file.
- Figure captions begin with the term Fig. in bold type, followed by the figure number, also in bold type.
- No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.
- Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.
- Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

Figure Placement and Size

- Figures should be submitted within the body of the text. Only if the file size of the manuscript causes problems in uploading it, the large figures should be submitted separately from the text.

- When preparing your figures, size figures to fit in the column width.
- For large-sized journals the figures should be 84 mm (for double-column text areas), or 174 mm (for single-column text areas) wide and not higher than 234 mm.
- For small-sized journals, the figures should be 119 mm wide and not higher than 195 mm.

Permissions

If you include figures that have already been published elsewhere, you must obtain permission from the copyright owner(s) for both the print and online format. Please be aware that some publishers do not grant electronic rights for free and that Springer will not be able to refund any costs that may have occurred to receive these permissions. In such cases, material from other sources should be used.

Accessibility

In order to give people of all abilities and disabilities access to the content of your figures, please make sure that

- All figures have descriptive captions (blind users could then use a text-to-speech software or a text-to-Braille hardware)
- Patterns are used instead of or in addition to colors for conveying information (colorblind users would then be able to distinguish the visual elements)
- Any figure lettering has a contrast ratio of at least 4.5:1

Supplementary Information (SI)

Springer accepts electronic multimedia files (animations, movies, audio, etc.) and other supplementary files to be published online along with an article or a book chapter. This feature can add dimension to the author's article, as certain information cannot be printed or is more convenient in electronic form.

Before submitting research datasets as Supplementary Information, authors should read the journal’s Research data policy. We encourage research data to be archived in data repositories wherever possible.

Submission

- Supply all supplementary material in standard file formats.
- Please include in each file the following information: article title, journal name, author names; affiliation and e-mail address of the corresponding author.
- To accommodate user downloads, please keep in mind that larger-sized files may require very long download times and that some users may experience other problems during downloading.
- High resolution (streamable quality) videos can be submitted up to a maximum of 25GB; low resolution videos should not be larger than 5GB.

Audio, Video, and Animations

- Aspect ratio: 16:9 or 4:3
- Maximum file size: 25 GB for high resolution files; 5 GB for low resolution files
- Minimum video duration: 1 sec
- Supported file formats: avi, wmv, mp4, mov, m2p, mp2, mpg, mpeg, flv, mxf, mts, m4v, 3gp

Text and Presentations

- Submit your material in PDF format; .doc or .ppt files are not suitable for long-term viability.
- A collection of figures may also be combined in a PDF file.

Spreadsheets

- Spreadsheets should be submitted as .csv or .xlsx files (MS Excel).

Specialized Formats

- Specialized format such as .pdb (chemical), .wrl (VRML), .nb (Mathematica notebook), and .tex can also be supplied.

Collecting Multiple Files

- It is possible to collect multiple files in a .zip or .gz file.

Numbering

- If supplying any supplementary material, the text must make specific mention of the material as a citation, similar to that of figures and tables.

- Refer to the supplementary files as “Online Resource”, e.g., "... as shown in the animation (Online Resource 3)", “... additional data are given in Online Resource 4”.
- Name the files consecutively, e.g. “ESM_3.mpg”, “ESM_4.pdf”.

Captions

- For each supplementary material, please supply a concise caption describing the content of the file.

Processing of supplementary files

- Supplementary Information (SI) will be published as received from the author without any conversion, editing, or reformatting.

Accessibility

In order to give people of all abilities and disabilities access to the content of your supplementary files, please make sure that

- The manuscript contains a descriptive caption for each supplementary material
- Video files do not contain anything that flashes more than three times per second (so that users prone to seizures caused by such effects are not put at risk)

Appendix H: Guidelines for submission to Dementia applied to the Empirical Paper

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. Biomedical and overly clinical research articles will not be accepted.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at Sarah.Campbell@MMU.ac.uk and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should be placed on the title page. Your main text should include a Declaration of Conflicting Interests (if applicable), any notes and your References but should be completely anonymized.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding

Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

The journal is committed to facilitating openness, transparency and reproducibility of research, and has the following research data sharing policy. For more information, including FAQs please visit the SAGE Research Data policy pages.

Subject to appropriate ethical and legal considerations, authors are encouraged to:

- share your research data in a relevant public data repository
- include a data availability statement linking to your data. If it is not possible to share your data, we encourage you to consider using the statement to explain why it cannot be shared.
- cite this data in your research

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor’s Publishing Agreement. SAGE’s Journal Contributor’s Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Dementia offers offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'.

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.5 Reference style

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Book reviews must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Sarah Campbell Sarah.Campbell@MMU.ac.uk

5.1 ORCID

> As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.
>
> The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors

to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

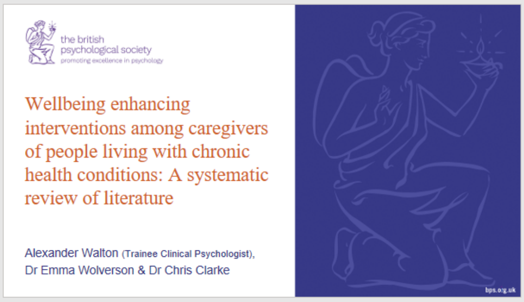
You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

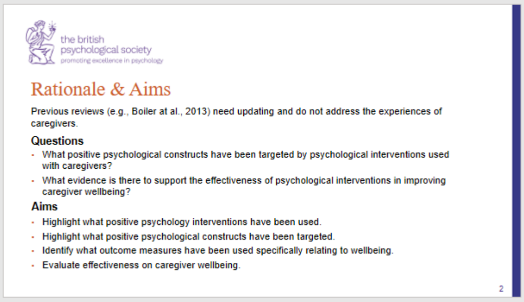
Appendix I: Literature Review presented at BPS Faculty of the Psychology for Older People National Conference on 28th June 2022



Wellbeing enhancing interventions among caregivers of people living with chronic health conditions: A systematic review of literature

Alexander Walton (Trainee Clinical Psychologist),
Dr Emma Wolverson & Dr Chris Clarke

bps.org.uk



Rationale & Aims

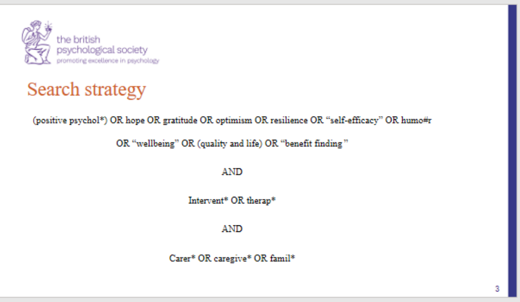
Previous reviews (e.g., Boiler at al., 2013) need updating and do not address the experiences of caregivers.

Questions

- What positive psychological constructs have been targeted by psychological interventions used with caregivers?
- What evidence is there to support the effectiveness of psychological interventions in improving caregiver wellbeing?

Aims

- Highlight what positive psychology interventions have been used.
- Highlight what positive psychological constructs have been targeted.
- Identify what outcome measures have been used specifically relating to wellbeing.
- Evaluate effectiveness on caregiver wellbeing.



Search strategy

(positive psychol*) OR hope OR gratitude OR optimism OR resilience OR "self-efficacy" OR humo#r

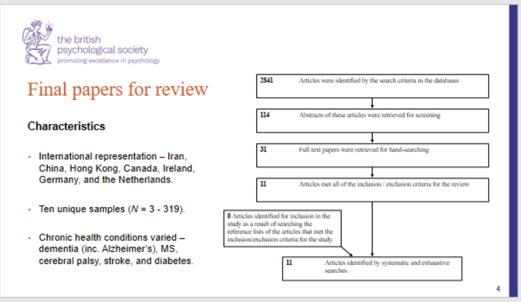
OR "wellbeing" OR (quality and life) OR "benefit finding "

AND

Intervent* OR therap*

AND

Carer* OR caregive* OR famil*



Final papers for review

Characteristics

- International representation – Iran, China, Hong Kong, Canada, Ireland, Germany, and the Netherlands.
- Ten unique samples (*N* = 3 - 319).
- Chronic health conditions varied – dementia (inc. Alzheimer's), MS, cerebral palsy, stroke, and diabetes.

2841 Articles were identified by the search criteria in the databases

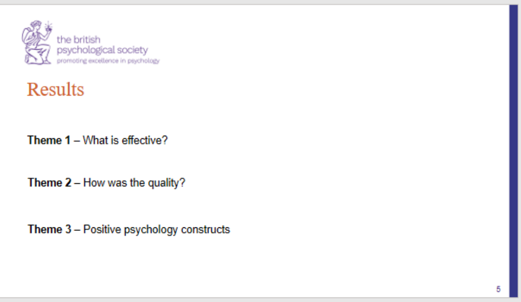
114 Abstracts of these articles were retrieved for screening

31 Full text papers were retrieved for hand-searching

11 Articles met all of the inclusion / exclusion criteria for the review

0 Articles identified for inclusion in the study as a result of searching the reference lists of the articles that met the inclusion/exclusion criteria for the study.

11 Articles identified by systematic and exhaustive searches.

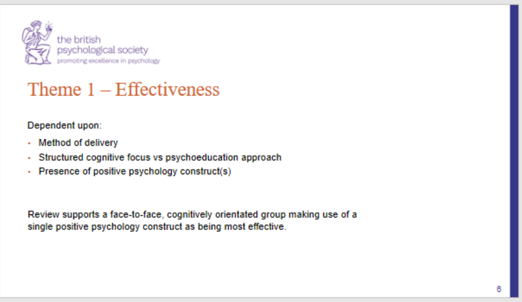


Results

Theme 1 – What is effective?

Theme 2 – How was the quality?

Theme 3 – Positive psychology constructs

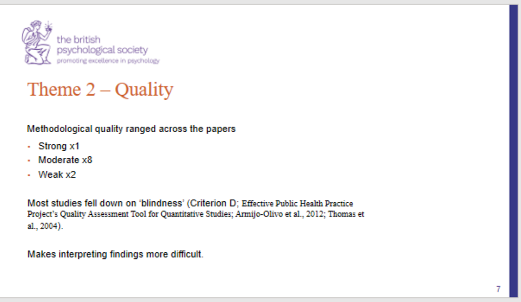


Theme 1 – Effectiveness

Dependent upon:

- Method of delivery
- Structured cognitive focus vs psychoeducation approach
- Presence of positive psychology construct(s)

Review supports a face-to-face, cognitively orientated group making use of a single positive psychology construct as being most effective.



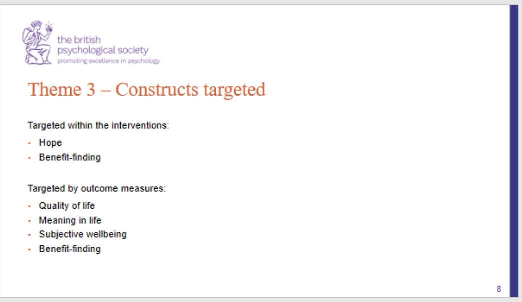
Theme 2 – Quality

Methodological quality ranged across the papers

- Strong x1
- Moderate x8
- Weak x2

Most studies fell down on 'blindness' (Criterion D; Effective Public Health Practice Project's Quality Assessment Tool for Quantitative Studies; Armijo-Olivo et al., 2012; Thomas et al., 2004).

Makes interpreting findings more difficult.



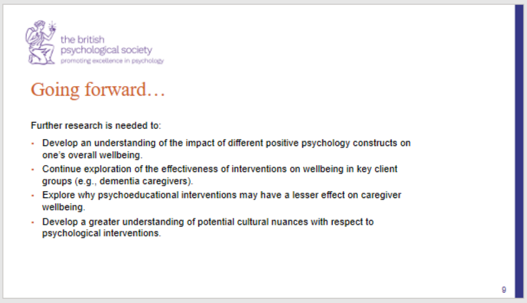
Theme 3 – Constructs targeted

Targeted within the interventions:

- Hope
- Benefit-finding

Targeted by outcome measures:

- Quality of life
- Meaning in life
- Subjective wellbeing
- Benefit-finding



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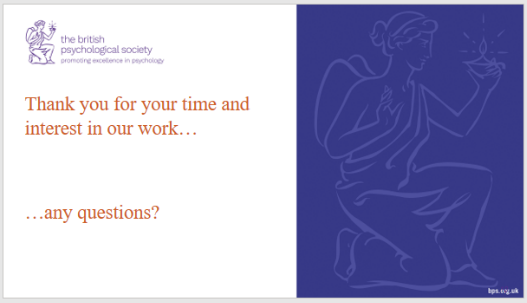
Going forward…

Further research is needed to:

- Develop an understanding of the impact of different positive psychology constructs on one's overall wellbeing.
- Continue exploration of the effectiveness of interventions on wellbeing in key client groups (e.g., dementia caregivers).
- Explore why psychoeducational interventions may have a lesser effect on caregiver wellbeing.
- Develop a greater understanding of potential cultural nuances with respect to psychological interventions.



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Thank you for your time and interest in our work…

…any questions?

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Appendix J: Epistemological Statement

Within research it is important to consider how a researcher's personal perspective may impact on the approach taken. This epistemological statement outlines the how the philosophical stance adopted by the researcher may have influenced the research.

Ontology relates to the belief and nature of reality (Goertz & Mahoney, 2012) whilst epistemology refers to how knowledge can be acquired (Willig, 2019) and therefore guides the research methods and theoretical underpinnings chosen by the researcher (Al-Saadi, 2014). Qualitative approaches tend to adopt a relativist ontology and constructionist epistemology, aiming to provide in-depth understandings of experiences and the associated meanings (Yilmaz, 2013). Due to the differing ontological and epistemological underpinnings aligned with qualitative and quantitative approaches to research, some suggest they are incompatible (Howe, 1992). However, a critical realist perspective can act as a middle ground between positivist and interpretivist positions (Bhaskar, 1975). Critical realism assumes findings provide insight into a phenomenon happening in the world, but that the findings need to be interpreted further in order to understanding the underlying factors and interactions (Willig, 2012).

This portfolio thesis was guided by a critical realist ontology and constructivist epistemology. Both papers of this portfolio – systematic literature review and empirical paper – assumed a qualitative paradigm, which is well suited to the constructivist position, due to the interactions between the researcher and participants/data.

In terms of the systematic literature review, a narrative synthesis of quantitative studies was undertaken. Part of the critical realist position involves utilising methods that fit with the nature of the research problem being focused upon (McEvoy & Richards, 2006). The systematic review aimed to collate and examine the available quantitative research to aid in meeting a qualitative gap within the literature base. This approach was therefore deemed acceptable.

Regarding the empirical paper, collecting qualitative data from participants about their personal views and experiences of hope and renewing hope fits with the critical realist view that there different and valid perspectives on reality to be held (Maxwell, 2012). Results, derived using the reflective thematic analysis method, were discussed with research supervisors and independent peers with experience in qualitative research. This was not done to seek out reliability of findings, but rather to ensure coherency in them. This approach was guided by the constructivist epistemology and the reflexive thematic analysis method's congruency with this view. The results became a co-construction between the participants and researcher, with the researcher taking an observer role that communicates their understanding of participant experiences (Ültanir, 2012). Due to the value placed on subjective skills being applied by the researcher in reflexive thematic analysis, a larger research team is not considered necessary or desirable (Braun & Clarke, 2021).

In summary, as characterised by the underpinnings of critical realism and constructivism, the systematic literature review and empirical study would have been impacted by the social and cognitive contexts of the researcher. Particularly, their assumptions and meanings held about facilitators and barriers, experiences of hope and caregiving, experiences of people living with dementia or other long term health conditions, and service delivery. Reflections, through the use of self-reflection, diary keeping, and discussions with supervisors, were hope to minimise the degree of inaccuracy when constructing knowledge from the experiences shared by participants.

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Appendix K: Reflective Statement

This statement reflects on the process of carrying out this research and encompasses all aspects of the research process, to consider what I have learned about my approach to research and what I have learned that will help me in future research endeavours.

People ask, “why dementia?” and my answer is that it was basic maths to me. A combination of two interests, like the overlapping portion of a Venn diagram. Throughout childhood and early adulthood, I spent a great deal of time with my maternal grandparents, as well as their friends and neighbours. They were a safe haven for me, a place of comfort away from the stresses and anxieties that whirled around me at home. Naturally, I would say, I become increasingly more comfortable in the company of the older generations. The stories they would tell about their childhoods and how things have changed so much across their lives, appearing somewhat unrecognisable to some these days. I found these moments, listening to every word they had to say, captivating. By the time I made it to college I knew I wanted to work in clinical psychology, and all the years spent with my grandparents and their generation, it made me want to spend my career listening to the stories of older people. Hearing about all they have experienced and overcome, and their views on what is yet to come for them. So that, of course, is why older people. But why dementia specifically? That is where my mum comes in. My mum lives with primary progressive multiple sclerosis, which for anyone reading this who doesn’t know, is a life-limiting neurodegenerative condition. One of the ways my mum’s condition influenced me was getting me interested in the brain and when things don’t work how they should because it’s become damaged in some way. In a nutshell, my mum’s condition means that her central nervous system is wasting away and shutting down, so her mind and body can’t function as they normally would. When you take older people and neurodegeneration, where they meet is where dementia lies.

The project started out life focussing on the people living with dementia. Most research in dementia is focused on those living with it rather than their caregivers. There were still many areas that required exploration, and so it initially felt right to head down this path. My own theoretical preference is in positive psychology. I suppose this has been, in part, borne out of a bias against the negative focus within clinical practice that has been reaped from overmedicalisation of services. Thinking back to when I was involved in providing care for my mum, although I could acknowledge the decline of her physical, psychological, and social health and wellbeing, I never like to focus on that angle. I preferred to make use of humour so see her smile and to help brighten her day, whilst also hoping each day that her multiple sclerosis would progress as slowly and kindly as possible. Between the second and third iterations of the project proposal, I had been reflecting more on my time at home caring for my mum. This led me to exploring a different part of the dementia literature – their caregivers. Keeping in mind the desire to have positive psychology at the project’s heart, hope and caregivers of people living with dementia began to emerge as an area lacking attention but brimming with potential, and a clear need for meaningful exploration. Little valuable research has been published addressing the experiences of carers of people living with dementia, especially on ways of effectively support them in remaining hopeful. I discussed my thoughts with my research supervisors and the decision was made. I scrapped what I had begun to formulate for my third research proposal and started work on rewriting it to focus on caregivers. From here the systematic literature review and empirical papers started to make their way into existence, one line on Word at a time.

The literature review focuses on caregivers more broadly, which was largely for practical reasons. My supervisors and I were conscious that interventions for those caregiving in dementia was not a highly published area of the literature, especially when factoring in positive psychology. Therefore, we made the decision to look wider to capture enough papers to do some meaningful exploration. In the end, half of the papers were regarding carers of people living with dementia, which meant it still fit quite well with the dementia-focussed empirical paper. Or at least I felt and still feel that way. Throughout the course of my research, but more so when conducting the systematic literature review, I have had to carefully reflect on the assumptions I hold and how they might influence the findings. This need to reflect was particularly evident when I included a study looking at a hope intervention for caregivers of people living with multiple sclerosis. While it is not possible to completely set aside my own perspective, I have attempted to use self-reflection to minimise the impact my own values, beliefs and experiences had on designing, implementing, and interpreting my research.

When you start on the doctorate, course staff and other trainees tell you not to underestimate the time and energy needed to complete the systematic literature review. Until you start getting into the review, developing search terms, applying them, narrowing down the pool of papers until you can finally analyse and synthesise the data, it doesn’t quite hit you just how right they were. So, for any fourth- or fifth-year trainees reading this, please do not underestimate how long it takes. It is a very long process. I will, however, say that I have ended up finding the systematic literature review pleasurable overall. Maybe even more so than the empirical. Something I am glad I chose to do for my review is write it for an international journal. This meant that I had to look at statistics from across the globe and it was essential I try to include as many papers from outside the UK as I could. What this did was it allowed me to discover the amazing caregiver intervention work being conducted around the world. This gives me a warm sensation in my heart and stomach. I'm pretty sure it isn't heartburn or indigestion, so it must be a good thing. I just can't place my finger on exactly what the feeling is, but I'm glad it's there. Perhaps it is knowing that there are people out there who do care about caregivers and want to help them too. I found that the systematic nature of the review, which meant the process had to be structured and organised, helped with managing it once I got into the swing of things. This being because I find clear order comforting and easier to follow. One of the challenges in the literature review was at the start, when defining the search terms. 'Positive psychology' needed to be one of the key components of the search, however, it is such a broad area and appeared difficult to accurately represent within the search. I wondered how many terms were enough to be considered inclusive, and how many would be too many? In the end, expert guidance from my supervisors and consideration of other positive psychology reviews, ten terms were chosen, and we were satisfied that the search was not being limited.

Narrowing down the pool of papers that would ultimately be reviewed through up its own challenges. I had opted for Sin and Lyubomirsky's (2009) definition of a positive psychology intervention; however, I think that in hindsight this is to broad and vague a definition. I feel as though it has left too much open for subjectivity when deciding if a study does in fact have a 'positive psychology intervention' or not. Then adding in the further inclusion criteria of a paper needing to use at least one positive outcome measure aimed at targeting wellbeing, directly or indirectly, I lost some papers that could have been valuable. I must consider though that I wanted the review to have a positive psychology focus, therefore, studies that exclusively utilised negative outcome measures (i.e., depression, burden, distress), were not congruent with my aims and values.

In contrast to the systematic literature review, I found surprisingly little pleasure in designing and conducting my empirical study. Going in the doctorate, I had big dreams for what I wanted to achieve with my empirical. I thought, “you know what, we can do this, let’s design a brand-new intervention, let’s create something that will help and change lives”. It didn’t take too long for reality to hit me, square in the face. I may have been a little ambitious. Naïve even. Reflecting on where my empirical has ended up, I think it has still been a meaningful and worthwhile piece of research. And who knows, it may even be the starting point for a stream of studies that lead to change for the better. So, I guess, watch this space!

One of the hardest parts of my empirical has, by far, been recruitment of participants. Based on the recommendations for doctoral research using thematic analysis (Braun & Clarke, 2013), the aim was to recruit at least ten caregivers of people living with dementia. I started in November 2021 by creating a poster and putting it up on social media (Twitter) and emailing a couple of local dementia support groups to seek their support in recruiting carers. Weeks went by and nothing came about. No real interest registered. Then, in January, I suddenly had four people wanting to arrange interviews for February. I felt like we had finally made some progress and that it was up from here. I conducted the interviews and continued to send out tweets to seek more participants. Things slumped again, with no one else being able to commit to an interview and silence from the support groups. My supervisors and I had some discussions and came up with a plan. I started to email more and more support groups and charities, aiming further afield this time. I also started to include Facebook and LinkedIn in my social media efforts, and had an advert placed in the university’s staff newsletter. Reluctantly, due to anxiety, I had a brief interview on a BBC radio show as an alternative avenue to spreading the word. Since Covid-19 hit, the dementia and caregiver populations have become harder to access for research, which is something we had considered when designing the study, but we never anticipated struggling quite this much to recruit. In the end, we succeeded in getting five caregivers to share their views and experiences of renewing hope. Personally, I have found hope for the success of my research to be a rollercoaster. And anyone who knows me well, knows that I'm not the biggest fan of theme parks and rollercoasters, so found this difficult. Disheartening at times. Would I like to have gained more participants? Yes. Do I think that my research is less meaningful because of such low recruitment levels? Possibly. Do I nevertheless believe that the views and experiences participants shared with me are incredibly valuable, powerful, and important? Absolutely!

My systematic literature review findings suggested a group cognitive intervention rooted in a single positive psychology construct could be important for enhancing caregiver wellbeing. My empirical findings suggested that caregivers of people living with dementia may value reality, recognition, and agency in support for renewing their everyday hope. I had the opportunity to share my literature review's findings at the annual Faculty of the Psychology for Older People national conference, which was held online this year. They received a good reception and despite my anxieties about presenting to such a knowledgeable and respected group, I thoroughly enjoyed the experience. The three Yorkshire training courses have for the past few years held a conference for the final year trainees to share their empirical findings, which meant I also had the opportunity to share those. Although only a small audience, it again felt good to be able to share what I had found and to hear others' thoughts and questions. I do remain conscious that both papers have small samples, therefore, I must be cautious when disseminating findings and careful not to declare sweeping generalisations or definitive statements. Although these papers are just small qualitative pieces, I am hopeful that there is value in the contributions they make to the literature out there, and that they can generate further interest in conducting research. Every little helps – no, I don’t mean Tesco clubcard prices.

There remains a paucity of research examining the most effective ways to enhance caregiver wellbeing, especially with a shift in focus toward positive psychology, and of research exploring how hope is best supported in caregivers of people living with dementia. My research has but scratched the surface of what can be looked at in this area and added a small donation to the growing literature of caregivers, dementia, and positive psychology. Recognition of caregivers was identified in my study, and I think that is something research needs to reflect going forward. They are the experts in their own experiences and can offer a world of insight, including in the development of support for the caregiving community. Future research needs to consider the value of co-production – from inception to conclusion, proposal to presentation.

In summary, given all that has happened over the past three years in my personal life and with university, and given the context of Covid-19, I’m almost in disbelief that things are coming to an end. As I type out this very line, it still hasn’t quite hit me fully, yet I think, just how big an achievement it is to have made it to the end of this research process. There have been ups and downs, which have all had there placed in the end, and steered me toward where I am now. The patience of my supervisors has been extraordinary and very much appreciated. I know that I should take this as my achievement and enjoy the knowledge that I made it, but I truly could not have got here without Emma and Chris by my side.

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