

Interventions for Informal Caregivers of People Living with Dementia:
A review of educational interventions for informal caregivers in low- and
middle-income countries and an empirical study of a Dementia Awareness for
Caregivers course in the United Kingdom

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Part One is a systematic literature review of interventions for informal caregivers of people living with dementia in low and middle-income countries. The review focusses on interventions with educational components and includes 18 papers detailing 17 studies. The review includes appraisal of the research quality and comparison of intervention characteristics, outcomes, and educational component features. It highlights the need for more high-quality research into potentially promising caregiver interventions, with group-based, multi-component interventions appearing to be the most effective at this stage.

Part Two outlines a feasibility and acceptability study of an online Dementia Awareness for Caregivers course delivered to informal caregivers of people living with dementia in the United Kingdom (UK)(DAC-UK). This paper reports on the quantitative outcomes of the study in terms of recruitment, retention, adherence, and attendance rates as well as exploratory analyses of five caregiver outcome measures, measured at baseline and at follow-up. The results indicate that the DAC-UK course is both feasible and acceptable, with some limitations in terms of attendance and positive trends in terms of impact on quantitative caregiver outcomes. This is a joint project with fellow Trainee Clinical Psychologist, Ria Patel, whose paper analyses the qualitative feedback from interviews with caregivers who attended the DAC-UK course.

Part Three is a critical appraisal reflecting on this thesis project. Discussion focusses primarily on Part Two considering personal reflections, the research process, and wider implications and recommendations.

Impact Statement

This thesis project contributes to the research literature on interventions for informal caregivers of people living with dementia, and in doing so offers value not only academically but also clinically. Given the increasing number of people living with dementia and therefore, the increasing number of informal caregivers, this is an important area of research worthy of this and ongoing further attention.

The systematic literature review identified and addressed a gap in the research as it is the only review, at present, to specifically focus on caregiver interventions, which contain an educational component, trialled in low- and middle-income countries (LMICs). The review appraised the quality of the studies and compared their design and efficacy in terms of dosage, delivery methods, and educational content. Based on these evaluations, recommendations were given in terms of necessary high-quality future research focussing on unpicking the active mechanisms within the interventions and considering the feasibility to allow for translation from academic studies to public health implementation. The review highlighted that at present, there is limited research into interventions for informal caregivers of people living with dementia in LMICs, especially in comparison to high-income countries (HICs). In doing so, the review has provided strong support for further research to address this global dementia care inequity especially given the promising findings, in terms of caregiver outcomes, of many of the studies reviewed. The findings of the review will be submitted to a relevant peer-reviewed academic journal to draw further attention to the need for research in this area.

The empirical study detailed a mixed-methods feasibility and acceptability study of the Dementia Awareness for Caregivers (DAC) course adapted for online delivery to informal caregivers of people living with dementia in the United Kingdom (UK). It formed part of a joint thesis project with Ria Patel, supervised by Prof Aimee Spector and Dr Charlotte Stoner. The study built on the initial development and promising field tests of the international DAC course template in LMICs (Stoner et al., 2022) by trialling it in the UK for the first time. It also

adapted the course for online delivery due to the ongoing COVID-19 pandemic and the need for virtually accessible caregiver interventions. The study found the DAC-UK course to be both feasible and acceptable to UK caregivers, with qualitative feedback also supporting intervention impact on caregiver experiences and behaviours. The study highlighted that there is currently no evidence-based brief, proactive, and adaptable intervention recommended in a public health context across the UK. The evidence from this study suggests that the DAC-UK is a promising option to address this gap in public healthcare. A larger scale randomised control trial is needed to further support the present findings, considering different participant samples and outcomes as well as the cost-effectiveness of the intervention. These results are in the process of being submitted for publication in a peer-reviewed academic journal to support this important ongoing research.

Table of Contents

List of Tables.....	9
List of Figures	9
Acknowledgements.....	10
Part One: Literature Review	11
Abstract	12
1. Introduction.....	13
2. Method.....	15
2.1. Literature Search Strategy	15
2.2. Inclusion and Exclusion Criteria	17
2.3. Screening and Selection	18
2.4. Quality Appraisal.....	18
2.5Data Extraction and Intervention Evaluation.....	20
3. Results.....	20
3.1. Included and Excluded Studies	20
3.2. Overview of Studies	23
3.3. Quality Appraisal.....	23
3.4. Interventions.....	38
3.4.1. Educational.....	38
3.4.2. Therapeutic.....	38
3.4.3. Support.....	39
3.4.4. Multicomponent	39
3.5. Intervention Delivery Characteristics.....	41
3.5.1. Group vs Individual	41
3.5.2. Intervention Length and Dosage.....	42
3.5.3. Internet-based vs In-person.....	43
3.6. Educational Component	44
4. Discussion.....	44
4.1. Summary	44
4.2. Nature of the Interventions	46
4.3. Education Delivery and Content	47
4.4. Clinical Implications and Future Research	48
4.5. Limitations.....	49
5. Conclusion	52
References	53

Part Two: Empirical Paper	63
Abstract	64
1. Introduction.....	65
2. Method.....	68
2.1. Design.....	68
2.2. Ethical Approval	69
2.3. Participants	69
2.4. Intervention – Dementia Awareness for Caregivers (DAC) Course	70
2.5. Adaptation of DAC Course for the UK.....	70
2.6. Procedure.....	73
2.7. Outcome Measures.....	74
2.7.1. Primary – Feasibility and Acceptability	74
2.7.2. Secondary – Quantitative Outcome Measures.....	74
2.8. Data Analysis.....	76
3. Results.....	76
3.1. Adaptation of DAC Course for the UK.....	76
3.2. Main study – Outcomes	77
3.2.1. Primary - Feasibility and Acceptability.....	77
3.2.2. Secondary – Quantitative Outcome Measures.....	79
4. Discussion.....	82
4.1. Summary	82
4.2. Feasibility and Acceptability	83
4.3. Caregiver Outcomes.....	84
4.4. Strengths and Limitations	84
4.5. Implications for Future Research.....	87
4.6. Implications for Clinical Practice	89
5. Conclusion	90
References	91
Part Three: Critical Appraisal	98
Introduction.....	99
Why this Research?.....	99
Study Design	101
Outcome Measures.....	103
Recruitment	105
Facilitating the Intervention	106

Clinical Impact.....	107
Recommendations	108
Conclusion	110
References	111
Appendices	115
Appendix 1 - Search Terms	115
Appendix 2 – Overview of contributions to joint thesis research project.....	122
Appendix 3 – Ethical approval letter from UCL Research Ethics Committee	123
Appendix 4 – Participant consent form	125
Appendix 5 – Study poster advertisement	127
Appendix 6 – Participant information sheet.....	128
Appendix 7 – Email sent to participants.....	131
Appendix 8 – Participant demographics questionnaire.....	132
Appendix 9 – End of participation information sheet.....	133
Appendix 10 – Short Sense of Competence Questionnaire.....	135
Appendix 11 – Approaches to Dementia Questionnaire (ADQ-19)	136
Appendix 12 – Short Form Zarit Burden Interview (ZBI-12)	137
Appendix 13 – Quality of the Caregiver Patient Relationship (QCPR): Carer version.....	138
Appendix 14 – The Gain in Alzheimer’s Care Instrument	140
Appendix 15 – Feedback from Stakeholders	141

List of Tables

Part One: Literature Review

Table 1: Overview of included studies.....	23
Table 2: Overview of Quality Assessment.....	33
Table 3: Overview of intervention designs and education components.....	36

Part Two: Empirical Paper

Table 1: Overview of the Dementia Awareness for Caregivers Course.....	71
Table 2: Participant Demographics.....	78
Table 3: Baseline Independent Samples T-tests.....	80
Table 4: Within-subject Means and Between-subject Effects at Follow-up.....	81

List of Figures

Part One: Literature Review

Figure 1: Downs and Black Checklist Question 27.....	19
Figure 2: Flow Diagram of Literature Identified, Excluded, and Included.....	21

Part Two: Empirical Paper

Figure 1: Study Recruitment and Retention Flowchart.....	77
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Part One: Literature Review

A systematic review of educational interventions for informal caregivers of people living with dementia in low and middle-income countries.

Abstract

Aims: With the increasing prevalence of dementia worldwide, there is a growing need for an integrated global approach to dementia care considering all stakeholders and the diverse needs of different populations. Despite increasing research demonstrating benefits of educational interventions for informal caregivers of people living with dementia (PLWD) in high-income countries, (HICs) much less is known about these interventions in low- and middle-income countries (LMICs). The review aimed to identify and synthesise the current research on interventions for caregivers of people living with dementia in LMICs, with a particular focus on the educational components.

Method: Four databases (PsycINFO, Medline, Web of Sciences and Scopus) were searched, alongside Google Scholar and reference lists. The Downs & Black checklist (Downs & Black, 1998) was used to quality assess the papers and data relating to intervention characteristics, outcomes and educational component features were gathered for comparison.

Results: Eighteen papers detailing 17 studies were included. Comparison across studies was difficult due to diverse methodological approaches, intervention structures and outcomes. Study quality was also variable, with higher quality studies including control groups and randomisation. Four studies had education as the primary focus, and the majority of interventions utilised multicomponent and group-based designs. Interventions that included group delivery tended to find significant results for more of the measured outcomes than individual approaches. Intervention length did not appear to influence efficacy, with shorter interventions just as effective, if they incorporated regular delivery and an average intervention dosage of around 12 hours.

Conclusions: This review has highlighted that research into educational interventions for caregivers in LMICs is a promising avenue to pursue. A multicomponent group intervention trialled in Egypt (Shata et al., 2017) provided particularly promising findings in terms of caregiver mental health, burden, and knowledge outcomes. Attention needs to be given to understanding the active mechanisms within interventions. Intervention development in conjunction with HICs and caregivers, will allow for designs that can be tailored to meet universal and culturally specific needs, whilst accounting for feasibility of implementation and equity for dementia care worldwide.

1. Introduction

It is estimated that over 50 million people globally are currently living with dementia (Alzheimer's Disease International, 2019) and this figure is set to continue to rise. Reports estimate that over 74 million people will be diagnosed by 2030, with 63% of these individuals living in low- and middle-income countries (LMICs) (Alzheimer's Disease International, 2015). These statistics highlight the need for an integrated global approach to dementia care and management, with consideration given to the diverse needs of different countries, cultures, and communities (Alladi & Hachinski, 2018).

Many people living with dementia across the world are cared for and supported by informal or family caregivers (Gallagher-Thompson et al., 2012). For example, within the United Kingdom (UK) alone, informal caregivers contribute the equivalent economic value of £11.6 billion providing over 1.34 billion hours of unpaid care to people living with dementia (Prince et al., 2014). These rates will continue to rise as the prevalence of dementia increases. Data regarding the frequency and economic cost of informal caregiving in LMICs is somewhat lacking in comparison (Dominguez et al., 2021; Mattap et al., 2022). Some evidence suggests that familial caregivers are responsible for the majority of the care (Fam et al., 2019) especially as many LMICs often do not, at present, have established dementia care policies or public health initiatives (Dominguez et al., 2021; Wang et al., 2014). High-income countries (HICs) have started to develop and implement diagnosis and treatment policies (Corbett et al., 2012; European Union, 2015), such as National Dementia Plans (ADI, 2019), which will increase awareness and support, but further work is still needed.

Within this high prevalence of informal caregiving, research indicates that the caregiving role has a significant impact on those who take it on (Brodaty & Donkin, 2009) encompassing increases in stigma (Kahn et al., 2016), burden (Smith et al., 2018) and mental health difficulties (Black et al., 2013). It is worth noting that many of the studies investigating these impacts are based on HIC populations. More recent research, however, suggests that the negative impact of caregiving is even greater for those from LMICs due to

the lack of public health infrastructure for dementia (Dominguez et al., 2021; Wang et al., 2014). In terms of stigma, studies have found both enacted and implied stigma within communities in Nigeria and South Africa (Adebiyi et al., 2016; Mkhonto & Hanssen, 2018) and this research suggests that the dearth of educational support for caregivers and communities allows such stigmas to propagate. Alongside this, Changoor (2019) argues that the burden of dementia is greater in LMICs, supported by studies which detail an “amplified” burden on caregivers (Nguyen et al., 2021). This amplification may be in part due to cultural narratives of collectivism and family involvement meaning family members are assumed to take on caregiving roles and are also reluctant to ask for professional help for fear of social judgement (Wang et al., 2012) but also due, again, to reduced public awareness and education (Mushi et al., 2014). Furthermore, research has also found that distress is higher in caregivers in LMICs compared to HICs (Wang et al., 2015) with caregivers resigned to a role of “hardship” and “desperation” (Nguyen et al., 2021). Wang et al. (2014) put forward that this higher distress may be due to a lack of awareness about dementia as a neurodegenerative disorder rather than a normal part of ageing. This is mirrored in qualitative feedback from caregivers in LMICs around the lack of and need for psychoeducational interventions for caregivers (Abaasa et al., 2021; Khan et al., 2017).

Given the significant role played by informal caregivers and the resulting impact on them, there is a large body of research into possible interventions to support them. A recent review (Cheng et al., 2019) detailed the different categories of interventions that have been trialled including psychoeducation, counselling and psychotherapy, multi-component and mindfulness based. A substantial number of studies highlight the value of interventions based on education around dementia. Reviews indicate that these interventions lead to reduced anxiety and depression symptoms, reduced burden and increased quality of life for caregivers (Frias et al., 2020) as well as caregivers reporting an enhancement in their ability to care due to a better understanding of the illnesses (Gitlin et al., 2010; Kwok et al., 2013). These findings corroborate the aforementioned research emphasising the importance of public education and awareness of dementia in mitigating the impact of the caregiving role.

Furthermore, the World Alzheimer's Report (Alzheimer's Disease International, 2019) endorsed targeted public health campaigns worldwide as its first recommendation. An educational focus also limits the resources and timescale needed for the interventions, especially when they are delivered online, which then makes them a more cost-effective option for governments to consider implementing (Christie et al., 2021). This is especially relevant for LMICs where there may be a lack of funding for more elaborate interventions (Hinton et al., 2019).

Despite the clear need for and likely benefits of educational interventions for informal caregivers, the majority of studies reviewed have been carried out in HICs (Drummond et al., 2019; Frias et al., 2020). Recent reviews of caregiver intervention studies in China and Asia found that over half of the studies had been carried out in HICs (Hinton et al., 2021; Ma & Saw, 2020) and a systematic review of culturally adapted interventions featured a large proportion of studies delivered in HICs to minority groups rather than in LMICs themselves (James et al., 2021). There are no systematic reviews, therefore, that have considered caregiver interventions with educational components that have been trialled in LMICs. This review intends to address this gap in the literature, based on the following research aims:

- To identify interventions with an educational component for informal dementia caregivers in LMICs.
- To appraise the potential effects and quality of these intervention studies.
- To make recommendations about future research regarding educational interventions for informal dementia caregivers in LMICs

2. Method

2.1. Literature Search Strategy

The systematic literature search was conducted across four databases: PsycINFO, Medline, Web of Sciences and Scopus. The searches were completed using OVID and EBESCO interfaces. The search terms used were developed based on terms used in similar

systematic reviews (Stoner et al., 2021). These were then tailored to the databases being searched and refined through an iterative search process to limit both unintended paper inclusion and exclusion. Google Scholar was also searched to capture any literature that was not found via the database searches.

Examples of search terms used to identify the population of people living with dementia included “Dementia” or “Alzheimer*” or “Lewy bod*” or “vascular dementia” or “cognitive impairment” alongside “carer*” or “caregive”. A list of LMIC search terms developed by the Cochrane Groups for CENTRAL (Cochrane EPOC, 2020), which are based on the World Bank Data, was used and included examples such as “low income countr*” or “underserved nation” or “Africa” or “Latin America” or “democratic republic of the congo” or “democratic republic congo” or “congo”. Search terms for the interventions included “support” or “training” or “intervention” or “course” or “training” or “group” or “trial” or “education” or “awareness”. These examples can be found within the exhaustive list of search terms in Appendix 1.

Classification of HICs and LMICs was designated according to the World Bank (2022). In some cases, countries are categorised as LMICs but there are some areas or regions that are classified as HICs. For example, China is currently recognised as a LMIC but Hong Kong, a special administrative region, is classified as a HIC. In these instances, the region where the study was carried out was screened to determine study eligibility.

This review will consider all countries that are categorised as low or middle-income in alignment with other reviews in the area (Mattap et al, 2022; Stoner et al, 2022) and in order to capture as many interventions for evaluation as possible. There was no rationale for a stricter categorisation or more specific grouping into e.g., middle- and lower-income countries, as the aim was to consolidate learning from a wide range of settings.

2.2. Inclusion and Exclusion Criteria

Studies were included if:

1. They reported on an intervention that included a focus or component described as “educational”, “psychoeducational” or similar*
2. The intervention, including the educational component, was evaluated using formal research methodology (quantitative or qualitative).
3. The study population comprised of informal caregivers of people living with a diagnosis of dementia in the community.
4. The intervention was delivered in a country (or region of a country) categorised as being low- or middle-income (World Bank, 2022).

* For the purposes of this review, education and psychoeducation were defined as including teaching on dementia, for example the possible symptoms and prognosis. This could be alongside or incorporated into therapeutic support or training on coping strategies but must be present for study inclusion. Studies that included solely therapeutic interventions, with no reference to the above teaching of educational materials, were not included.

Studies were excluded if:

1. They were not peer reviewed.
2. They were reviews or protocols.
3. The intervention was also or solely delivered to the person living with dementia (PLWD).
4. The intervention was delivered in a high-income country or region.
5. The paper was not written in or translated into English.

2.3. Screening and Selection

EndNote software was used to extract, store, and screen the search results. Duplicates were removed and titles assessed against the inclusion and exclusion criteria. Subsequently, abstracts were screened, and full text articles were retrieved for the remaining studies. These full text reports were then also screened against the criteria before being accepted into the review. The reference lists of these accepted studies were also examined for further studies eligible for inclusion, which were then also assessed via the same process. All studies were screened for the country of intervention delivery via reference to the study title, abstract and method alongside reference to the institutional associations of the researchers. These countries were then checked according to the World Bank list of LMICs (World Bank, 2022).

2.4. Quality Appraisal

Given the limited research within this area and the resulting number of papers identified, formal quality appraisal of the studies was carried out for evaluation rather than to establish a quality threshold for inclusion in the review. As not all the studies included were randomised control trials (RCTs), quality was assessed using The Downs and Black Checklist. The checklist comprises of 27 items and is designed to assess a range of different study designs (Downs & Black, 1998). Many of the studies included in the review were pilot studies or underpowered so the last item on the checklist (see Figure 1) was adjusted to be scored as 'Yes', 'No' or 'Unable to determine' to capture simply whether each study was powered or not to detect significant effects. This adaption has been used in other systematic reviews (Korakakis et al, 2018).

Therefore, each study was scored out of a possible 27 points. Another researcher also independently scored 10% of the included studies using the checklist and a *k* statistic was calculated as 63.4% indicating a substantial level of agreement for interrater reliability (Landis & Koch, 1977). Following this, the researchers discussed their differences and scored another paper independently achieving a *k* statistic of 100%.

Figure 1

Downs and Black Checklist Question 27

Power

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

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

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

2.5. Data Extraction and Intervention Evaluation

All studies were evaluated in terms of general study characteristics. However, as the primary focus of this review was education, in-depth data extraction and evaluation was carried out for these components. This included considering the nature of the overarching intervention, the nature of the education delivery and the types of educational content, and each of these areas was split into relevant categories. The synthesis method for these categories was thematic and the categories were decided by the researcher during the evaluation process. This process was informed by other reviews in the area that had made similar classifications (Cheng et al., 2019; Gallagher-Thompson et al., 2012).

3. Results

3.1. Included and Excluded Studies

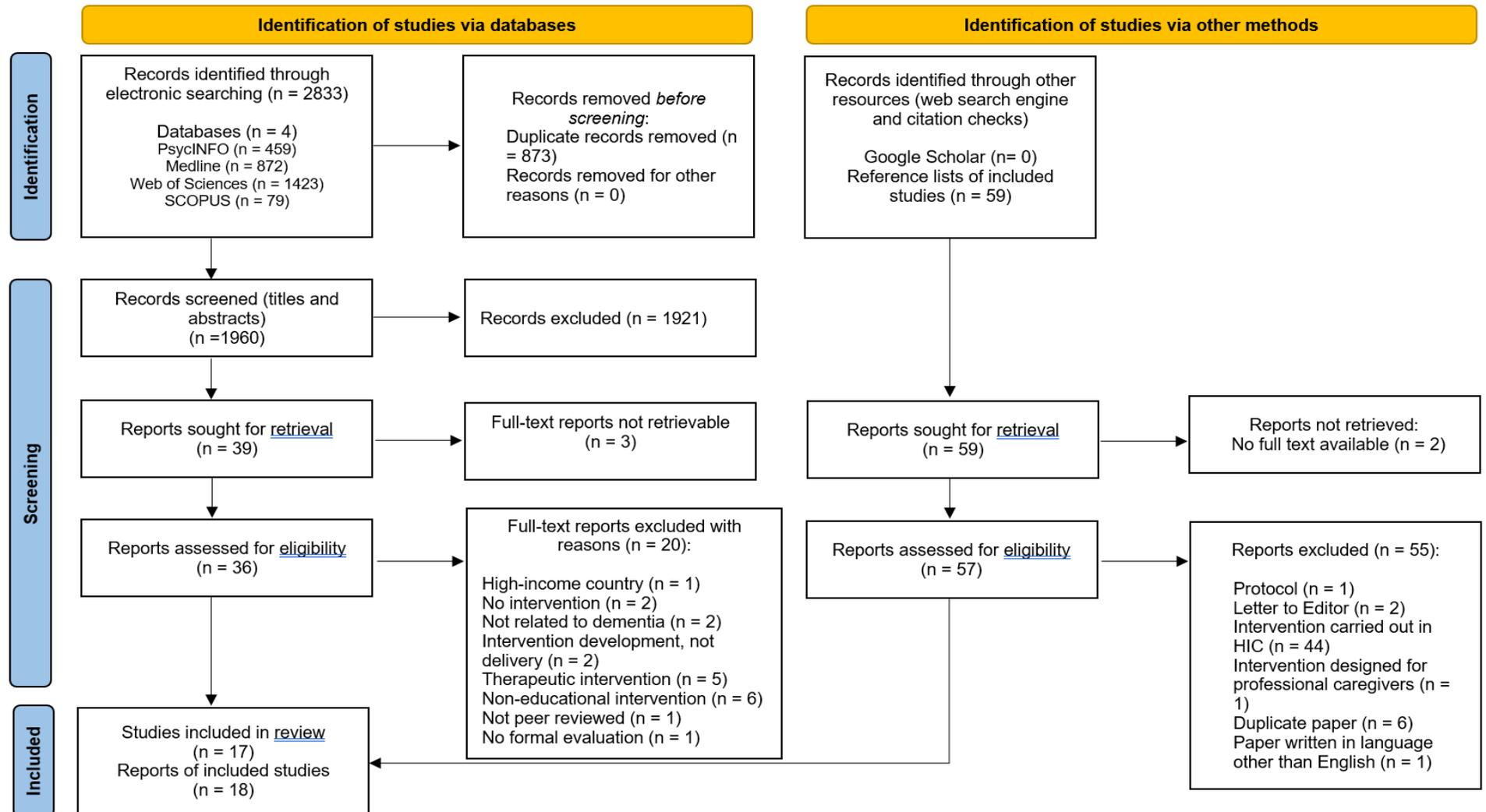
A total of 2833 records were identified. Duplicates were removed and the remaining 1960 papers were screened via titles and abstracts. During this stage, 1921 papers were excluded as not eligible. The remaining 39 papers were sought for retrieval and assessed for eligibility. Of these 39 papers, 23 were excluded for reasons such as the intervention was carried out in a HIC ($n=1$), the paper was not written in English ($n=2$), the intervention did not include an educational component ($n=6$) or was solely therapeutic ($n=5$), there was no active intervention ($n=2$) or was not related to dementia ($n=2$), the paper detailed intervention development not delivery ($n=2$), the paper was not peer reviewed ($n=1$) or the intervention was not formally evaluated ($n=2$). Two studies detailed the inclusion of caregiving “dyads” or “pairs”; however, the intervention was delivered solely to the caregiver, so the studies were included. This left 16 papers that detailed 15 studies.

There were 59 additional papers identified from the reference lists of the above included studies, of which 2 were included. The other 57 papers were excluded at this stage due to there being no full text available ($n=2$), the paper being a protocol ($n=1$) or a letter to the editor ($n=2$), the intervention being carried out in a HIC ($n=44$) or designed for professional caregivers ($n=1$), the paper being a duplicate ($n=6$) or the paper being written in a language other than English ($n = 1$). Therefore, 18 papers relating to 17 studies were included within the review.

Figure 2 provides an illustrative flow-chart of the literature screening process.

Figure 2:

Flow diagram of literature identified, excluded and included



3.2. Overview of Studies

Table 1 provides an outline of all the included papers including an overview of the study location, design, sample size, intervention details, outcome measures, significant results, and quality scores.

Studies were implemented across 11 different countries that covered four continents: South America, Asia, Europe, and Africa. All the papers were published between 2004 and 2022 and the samples ranged from 16 to 159 with an average sample size of 65. All the studies evaluated the interventions using quantitative outcome measures, there were no qualitative evaluations. There was a wide range of outcomes measured across the papers. In total, 36 different measures were used for caregiver outcomes and eight measures were used for people living with dementia. All of the studies found at least one significant result.

3.3. Quality Appraisal

Details of the quality appraisal can be found in Table 2. The quality assessment ratings ranged from 13 to 25 out of 27. The average score was 20.72. The lowest quality study was the educative support group in Iran by Javadpour et al. (2009) (13/27) and the highest quality studies were the 10/66 helping carers to care intervention in Russia and Peru (25/27) (Gavrilova et al., 2009; Guerra et al., 2011). Of the studies that scored more poorly, the most common reasons were no randomisation or blinding, a lack of clarity on intervention adherence and the study not being sufficiently powered to detect a clinically significant effect. None of the studies reported on or measured any adverse events resulting from the interventions.

Table 1

Overview of included studies

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
Randomised Control Trials	Gavrilova, Ferri, Mikhaylova, Sokolova, Banerjee & Prince, 2009	Russia <i>n</i> = 60 5 weeks	Control: Treatment as usual Sample recruited via medical centres	10/66 “Helping Carers to Care” Intervention 1 – Assessment (1 session) (carer knowledge of dementia and family care arrangements) 2 – Basic education (2 sessions) (introduction to dementia, the progression, causes, local care/treatment) 3 – Training on ‘problem’ behaviour (2 sessions) (e.g., personal hygiene, dressing, repeated questioning, aggression, wandering)	2.5 hours Weekly 30-minute sessions	Caregiver: - Zarit Burden Interview (ZBI) - Self-reporting questionnaire (SRQ-20) - Caregiver quality of life (WHOQOL-BREF) -Neuropsychiatric Inventory Questionnaire (NPI-Q) PLWD: -Neuropsychiatric Inventory Questionnaire (NPI-Q) -Dementia Quality of Life questionnaire (DEMQOL)	Significant reduction in burden (ZBI) for intervention group compared to control (<i>p</i> =.03)	25/27	
	Guerra, Ferri, Fonseca, Banerjee & Prince, 2011	Peru <i>n</i> = 58 5 weeks	Control: Waiting list Sample: Local survey and memory clinic	10/66 “Helping Carers to Care” Intervention 1 – Assessment (1 session) (carer knowledge of dementia and family care arrangements) 2 – Basic education (2 sessions) (introduction to dementia, the progression, causes, local care/treatment) 3 – Training on ‘problem’ behaviour (2 sessions) (e.g., personal hygiene, dressing, repeated questioning, aggression, wandering)	2.5 hours Weekly 30-minute sessions	Caregiver: - Zarit Burden Interview (ZBI) - Self-reporting questionnaire (SRQ-20) - Caregiver quality of life (WHOQOL-BREF) -Neuropsychiatric Inventory Questionnaire (NPI-Q) PLWD: -Neuropsychiatric Inventory Questionnaire (NPI-Q) - Dementia Quality of Life	Significant reduction in burden (ZBI) for intervention group compared to control (<i>p</i> <.001)	25/27	

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
						questionnaire (DEMQOL)			
	Hinton, Nguyen, Nguyen, Harvey, Nichols, Martindale- Adams, Nguyen, Nguyen, Nguyen, Nguyen, Nguyen, Nguyen, Nguyen, Nguyen, Tiet, Nguyen, Nguyen, & Pham, 2020	Vietnam <i>n</i> = 60 2 to 3 months	Control: Single 1:1 face to face educational session about dementia and written dementia resources Sample: Convenience through clustered local health services	REACH VN – manualised multicomponent intervention Home visits 4 core training sessions: 1 – Problem solving 2 – Mood management/cognitive restructuring 3 – Stress management 4 – Communication + 2 more session based on clinical judgment/ caregiver needs	Estimated 8.6 to 13 hours. Weekly 1- hour home visits	Caregiver: - Zarit Burden Interview (ZBI) (4 item) - Patient Health Questionnaire (PHQ-4) - Alzheimer's disease knowledge scale PLWD: None.	Significant decrease in burden in favour of intervention (ZBI) (<i>p</i> =.02) Significant decrease in PHQ-4 in intervention compared to control (<i>p</i> =.03)	24/27	Feasibility measured through recruitment and retention statistics.
	Shata, Amin, El-Kady & Abu- Nazel, 2017	Egypt <i>n</i> = 120 8 weeks – (post- measures after 3 months)	Control: Waiting list Sample: Convenience sample through hospital clinic	Multicomponent psychosocial intervention program 3 components: 1- Group psychoeducation (2 sessions) 2 – Brief group CBT (6 sessions) 3 – Group support sessions (parallel to all sessions)	6 – 8 hours Weekly 45–60- minute sessions	Caregiver: - Knowledge questionnaire - Hamilton Depression Rating Scale (HDRS) (Arabic) - Taylor Manifest anxiety scale (TMAS) - Zarit Burden Interview (ZBI) PLWD: - Mini mental state examination (MMSE)	Significant decrease in anxiety (TMAS), depression (HDRS) and perceived burden (ZBI) for intervention compared to control at 8 weeks and 3 months (<i>p</i> <.001) Significant improvement in dementia knowledge in intervention group compared to control (<i>p</i> <.001)	24/27	

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
	Dias, Dewey, D'Souza, Dhume, Motghare, Shaji, Menon, Prince & Patel, 2008	Goa, India <i>n</i> = 81 6 months <i>N.B. Visit frequency dependent on individual need, at least once a fortnight for 6 months but could be a lot more.</i>	Control: Waiting list Sample: Recruited through adverts and health services	Home Care Program Stepped care and tailored model. Delivered by home care advisors- - Basic education about dementia - Education about common behaviour problems and management - Caregiver support (e.g., in activities of daily living) - Referrals when behaviour problems escalated and needed medication intervention. - Networking of families to allow for support groups. - Advice regarding existing government schemes for elders	Average 9.225 hours (Mean home visits = 12.3, average time = 45 minutes) <i>N.B. Nine additional peer support groups also run (no length given)</i>	Caregiver: -Neuropsychiatric Inventory Questionnaire (NPI-Q) Distress subscale (D) - Zarit Burden Interview (ZBI) - General Health Questionnaire (GHQ) PLWD: -Neuropsychiatric Inventory Questionnaire (NPI-Q) (Severity subscale – S) - Everyday Abilities Scale for India (EASI)	Significant reduction in GHQ and NPI-Q (D) in the intervention group compared to control. (<i>p</i> -values not provided)	23/27	Dyad in study
	Tawfik, Sabry, Darwish, Mowafy & Soliman, 2021	Egypt <i>n</i> = 60 8 weeks	Control: Treatment as usual Sample: Identified by researcher at Cairo University hospital outpatient unit	Psychoeducational Program Main objectives: 1 - Giving information about different dementia behaviours (e.g., agitation, wandering) and tips to deal with them. 2 – Caregiver support and de-stress techniques Sessions included role playing, brainstorming, group discussion and videos.	8 hours Weekly 1-hour sessions	Caregiver: - Zarit Burden Interview (ZBI) - Arabic Quality of life in Alzheimer's disease questionnaire for caregivers (QoL-AD) PLWD: Arabic Quality of life in Alzheimer's disease questionnaire for patients (QoL-AD)	Significant improvement in ZBI scores for intervention group compared to control at post-measure (<i>p</i> <.001)	23/27	

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
	Pankong, Pothiban, Sucamvang & Khampolsiri, 2018	Thailand <i>n</i> = 72 8 weeks (follow-up at 12 and 20 weeks)	Control: Treatment as usual Sample: Invited through local hospitals	Enhancing positive aspects of caregiving program 6 group sessions covering: 1 – dementia knowledge/ADLs/behaviour management 2 – meditation and spirituality 3 – sharing experiences 4 – role modelling/verbal reinforcements 1 individual session + dementia care booklet	12 hours 6 x 2-hour sessions <i>Additional phone call, length not specified</i>	Caregiver: - Positive aspects of caring questionnaire (PACQ) - Thai general wellbeing schedule (TGWS) PLWD: None.	Significant increase PACQ in intervention compared to control at weeks 8, 12 and 20 ($p < .0001$) Significant increase in wellbeing (TGWS) scores over time ($p < .001$) but no significant difference between the groups	22/27	
	Tran, Nguyen, Pham, Nguyen, Nguyen, Nguyen, Harvey, & Hinton, 2022	Vietnam <i>n</i> = 60 2 to 3 months	Control: Single 1:1 face to face educational session about dementia and written dementia resources Sample: Convenience through clustered local health services	REACH VN – manualised multicomponent intervention Home visits 4 core training sessions: 1 – Problem solving 2 – Mood management/cognitive restructuring 3 – Stress management 4 – Communication + 2 more session based on clinical judgment/ caregiver needs	Estimated 8.6 to 13 hours. Weekly 1- hour home visits	Caregiver: REACH risk priority assessment (from REACH VA manual) (Variables: general health, caregiver frustrations, stress symptoms, general stress, behaviours, bother with behaviours) PLWD: None.	Significant decrease in caregiver frustration variable in intervention group compared to control ($p = .01$)	22/27	
	Baruah, Varghese, Loganathan, Mehta,	India <i>n</i> = 151	Control: educational e-book	Online iSupport Program 23 lessons related (with interactive learning situations) to	Online access for 3 months	Caregiver: - Zarit Burden Interview (ZBI) - Center for	Significant difference in ADQ-19 scores ($p = .030$) at post- treatment between	20/27	Feasibility measured through recruitment

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
	Gallagher- Thompson, Zandi, Dua & Pot, 2021	3 months	Sample: National advertising and recruitment	themes: - What is dementia? (1) - Being a caregiver (4) - Caring for me (3) - Providing everyday care (5) - Dealing with behaviour changes (10) + Relaxation activity after each lesson	<i>N.B.</i> <i>Carers</i> <i>encourage</i> <i>d to attend</i> 5+ <i>lessons</i>	Epidemiological Studies Depression-10 item scale (CES-D10) - Approaches to Dementia Questionnaire (ADQ) - RIS Eldercare Self-efficacy scale. - Mastery scale	treatment and control – treatment had increase in positive attitudes towards PLWD.		and retention statistics.
Quasi- experimental multi-arm designs	Magteppong & Yamarat, 2021	Thailand <i>n</i> = 60 8 weeks (follow-up at 20 weeks)	Pre/post parallel groups interventions study Control: Treatment as usual (handbook provided post- intervention) Sample: Purposive via local hospital records and day centre attendees	Modified Transtheoretical Theory of Stress and Coping (TTSC) Program (multicomponent) Aims: increase caregiver knowledge, reduce burden and increase quality of life Week: 1 – Group health education (handbook provided) 2 – Home visit (Stress, appraisal and coping) 3 -7 – Telephone follow-ups 8 – Home visit (Stress, appraisal and coping)	3.25 – 6.20 hours Weekly contact- 1 x group meeting 2 x home visits 5 x telephone follow-ups	Caregiver: - Dementia Knowledge Assessment (DKA) - Thai burden interview for caregivers of patients with chronic illness - World Health Organisation's Quality of life – Thai (WHO QoL) PLWD: None.	Significant increase in knowledge score for intervention compared to control at week 8 and 20 (<i>p</i> <.05) Significant difference in quality of life in favour of intervention compared to control at 8 and 20 weeks (<i>p</i> <.05)	22/27	
	Senanarong, Jamjumras,	Thailand	Randomised parallel	Counselling intervention for caregivers	3.75 hours	Caregiver: Neuropsychiatric Inventory	Significant decrease in NPI-Q scores in	22/27	

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
	Harmphadungkit, Klubwongs, Udomphanthurak, Pongvarin, Vannasaeng & Cummings, 2004	n = 50 6 months	group intervention study Control: Treatment as usual Sample: Recruited from hospital memory clinic	Content of group counselling and support sessions: - Sharing experiences - Information provided about techniques/coping - educational content (dementia prognosis and progression etc) -Adaptions to environment -Identifying needs and understanding behaviours	5 x 45-minute sessions (every 6-8 weeks)	Questionnaire (NPIQ) PLWD: - Thai mental state examination (TMSE) - Functional assessment questionnaire (FAQ) -Thai activities of daily living measure -Clinical dementia rating (CDR)	intervention group between baseline and month 6 ($p=.045$) but not between the groups		
	Zhang, Wu, Tang, Rong, Guo, Fang, Zhao, & Zhao, 2020	China n = 41 36 weeks	Pre/post parallel groups intervention study Control: individual telephone support Sample: Recruited from 2 hospitals	Caregiver self-management support intervention (C-SMS) Components: 1 – Illustrated educational booklet (3 volumes – basic dementia care knowledge, symptom and problem identification and interventions, knowledge and skills for self-management) and a booklet of local contact details and support options) 2 – 6 bi-weekly support group sessions (12 weeks) 3 – 3 educational presentations during a 6-month follow-up period	15 – 18 hours 6 x 2-weekly 2.5-3-hour group sessions + 3 presentations with length not specified (over 6-month follow-up period)	Caregiver: - Caregiver health related QoL (HRQoL) - Self-efficacy questionnaire for Chinese family caregivers (SEQCFC) PLWD: -Chinese version of the Disability Assessment in Dementia (DAD) -Neuropsychiatric Inventory-Questionnaire (NPI-Q)	Significant improvement in HRQoL in intervention compared to control ($p=.017$) Significant improvement in specific domains of self-efficacy for intervention compared to control: managing BPSD* ($p=.013$) and managing distress ($p=.034$)	20/27	Also measured physical outcomes – instances of caregiver metabolic syndrome Also measured retention and attrition statistics
Quasi-experimental pre-post/repeated measures	Zakaria & Ab Razak, 2017	Malaysia n = 16 12 weeks	No control Sample: Convenience	Cultural-based support group Facilitated by healthcare professionals.	12 hours 2-hour sessions every 2	Caregiver: - Caregiver strain index (CSI) - Hospital anxiety and depression scale (HADS)	Significant decrease in CSI scores from pre to post ($p=.01$) Significant	19/27	

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
single group designs			recruitment through a local memory clinic	Each session had 2 parts: 1- Psychoeducation session. 2 – Mutual sharing and problem- solving Theme examples: - Introduction to principles and role within support group - understanding dementia - practical caregiving skills - supports for caregivers - effective communication - safe and healthy environment	weeks.	- Caregiver quality of life (WHOQOL-BREF) PLWD: None.	improvement in specific domains of the WHOQOL-BREF from pre to post: physical ($p=.01$), psychological ($p=.006$) and environmental ($p=.002$)		
	Kuzu, Beser, Zencir, Sahiner, Nesrin, Ahmet, Binali & Cagdas, 2005	Turkey $n = 32$ 4 weeks	No control Sample: Recruited through hospitals, Alzheimer's association and community through word-of- mouth ad local media	Comprehensive educational program reinforced by an individualised component (CEPRIC) 3 components: 1 – General information session (dementia, behaviour disorders, home and daily life) 2 – Individualised educational component (specific problems identified through questionnaire) 3 – Educational booklet	Not specified	Caregiver: - Duke Scale - Beck depression scale (BDS) - Beck anxiety inventory (BAI) PLWD: -Mini mental state examination (MMSE)	Significant decreases in BDS ($p=.008$), BAI ($p=.01$) Significant decreases in Duke scale subscales of physical health concerns ($p=.001$) and general health concerns ($p=.004$)	18/27	Dyad in study Nursing diagnoses also given before and after intervention
	Fialho, Köenig, Santos, Barbosa & Caramelli, 2012	Brazil $n = 40$ 8 weeks	No control group No sample or	Cognitive-behavioural intervention program (Based on Training of Social Skills (TSS)) - Education	16 hours Weekly sessions (2 hours)	Caregiver: - Zarit Burden Interview (ZBI) - Quality of Life scale for caregivers of people living with Alzheimer's Disease	Significant reduction in reported NPI-Q symptoms ($p=.034$) Significant reduction	17/27	

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
			recruitment details	<ul style="list-style-type: none"> - Cognitive, emotional, and social skills training - Support/empathy - Social comparison and shared learning - Strategies to modify own behaviour - Reinforcing persistence and effort - Cognitive strategies - Diary/therapy schedule - Activity organisation and preparation 		<p>(QoL-AD)</p> <ul style="list-style-type: none"> - The list of stress symptoms (LSS) - Jalowiec Coping scale (JCS) - Trait Anxiety Scale (A-Trait) (from the State Trait anxiety Inventory (STAI)) - Major depressive episode module of the Mini International Neuropsychiatric Interview (NPI- Q MINI) 5.0. (DSM-IV). <p>PLWD:</p> <ul style="list-style-type: none"> -QoL-AD for PLWD (answered by family) - Mini mental state examination (MMSE) (only pre-intervention) -Disability assessment for dementia (DAD) (only pre-intervention) -Neuropsychiatric Inventory Questionnaire (NPI-Q) (only pre-intervention) 	<p>in trait anxiety scores (A scale – STAI) ($p=.005$)</p> <p>Significant improvement in PLWD QoL-AD ($p=.040$)</p>		
	Han, Guo & Hong, 2022	China $n = 159$ 3-6 months <i>N.B. Carers</i>	No control Snowballing sample via online forum and health	WeChat virtual community – professional facilitated peer support 6 elements: 1 – Peer emotional support 2 – Lectures and consultation (13	Online access for 3-6 months	Caregiver: - Self- Efficacy Questionnaire for Chinese Family Caregivers (SEQCFC) -Neuropsychiatric Inventory Questionnaire	Statistically significant decrease in stress (PSS-C) ($p<.05$), helplessness ($p<.001$) and depression (CES-D10) ($p<.05$)	17/27	

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
		<i>could enter the intervention at different time points between 0-3 months</i>	clinics	topics – e.g., dementia knowledge, care strategies, communicating) 3 – Technique support 4 – Reading 5 – Maintaining a friendly environment 6 – Participation and peer support		(NPIQ) - Perceived Stress Scale of Chinese version (PSS-C) - Center for Epidemiologic Studies Depression Scale (CES-D10) - Zarit Burden Interview (ZBI) - Learned Helplessness Scale PLWD: None.	Statistically significant increase in self-efficacy (SEQCFC) ($p < .05$)		
	Santos, Sousa, Arcoverde & Dourado, 2013	Brazil $n = 18$ 6 months	No control No sampling details given	Psychoeducational group (based on STAR-Caregivers model) Sessions included discussions about experiences, expressing emotions and educational lectures about dementia (types, BPSD* etc)	39 hours Weekly 90-minute sessions	Caregiver: - Caregivers version of quality of life in Alzheimer's disease scale(QoL-AD) - Zarit Burden Interview (ZBI) - Beck depression inventory (BDI) - Beck Anxiety inventory (BAI) PLWD: -Clinical dementia rating (CDR) - Pfeffer Functional Activities Questionnaire (FAQ) -Cornell scale for	Significant decrease in BDI scores between pre and post assessments ($p = .011$)	17/27	Santos, Sousa, Arcoverde & Dourado, 2013

Design	Authors/ Date	Location/ Participants (n)/Duration	Study Control/ Sampling	Intervention	Dosage	Outcome Measures	Significant Results	Quality Score	Comments
						depression in dementia (CSDD) -Neuropsychiatric Inventory Questionnaire (NPIQ)			
	Javadpour, Ahmadzadeh & Bahredar, 2009	Iran <i>n</i> = 29 8 weeks	No control Random sample (no further details given)	Educative support group Each session contained: - 30-minute educative talks providing information about dementia/challenging behaviours/problems faced by caregivers - 90-minute interactive activities including discussions and sharing experiences	16 hours Weekly 2-hour sessions	Caregiver: - Perceived Stress Scale-10 (PSS-10) - General Health Questionnaire (GHQ)(Farsi) - Neuropsychiatry Inventory (NPI) PLWD: - Neuropsychiatry Inventory (NPI) - Clinical Dementia Rating (CDR)	Significant decreases in PSS scores (<i>p</i> =.0001), GHQ scores (<i>p</i> =.0001), NPI scores (<i>p</i> =.001)	13/27	All female caregivers

Table 1 Key

*BPSD = Behavioural and psychological symptoms of dementia

** PLWD = Person living with dementia

Table 2

Overview of Quality Assessment

	Baruah et al., 2021	Dias et al., 2008	Fialho et al., 2012	Gavrilova et al., 2009	Guerra et al., 2011	Han et al., 2022	Hinton et al., 2020	Javadpour et al., 2009	Kuzu et al., 2005	Magteppong & Yamarat, 2021	Pankong et al., 2018	Santos et al., 2013	Senanarong et al., 2004	Shata et al., 2017	Tawfik et al., 2021	Tran et al., 2022	Zakaria & Razak, 2017	Zhang et al., 2020	
1. Clear hypotheses/aims/objectives?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Outcome to be measures in the introduction/method?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Participant characteristics described? (inclusion/exclusion)	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
4. Interventions of interest clearly described?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5. Principle cofounders described?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6. Main findings clearly described?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
7. Estimates of the random variability of the data for the main outcomes provided?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
8. All important adverse events that may be a consequence of intervention reported?	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
9. Characteristics of participants lost to follow-up described?	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10. Actual probability values reported for main outcomes?	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

(Except if <.001)

11. Subjects asked to participate representative of entire population?

Y	Y	U	Y	Y	Y	Y	U	Y	Y	Y	U	Y	Y	Y	Y	Y	Y

12. Subjects prepared to participate representative of entire population?

Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---

13. Staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?

N	Y	Y	Y	Y	N	Y	Y	Y	Y	U	U	Y	N	Y	Y	Y	Y
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14. Attempt made to blind study subjects to intervention received?

Y	Y	N	Y	Y	N	N	N	N	U	U	N	U	Y	U	N	N	N
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15. Attempt made to blind those measuring the main outcomes?

U	Y	N	Y	Y	N	Y	N	N	U	U	N	U	Y	U	Y	N	U
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16. Results based on “data dredging” made clear?

Y	Y	Y	Y	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
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17. In trials and cohort studies, analyses adjust for different lengths of follow-up, or in case-control studies, time between the intervention and outcome the same for cases and controls ?

Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
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18. Appropriate statistical tests?

Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
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19. Compliance with the intervention/s reliable?

N	U	Y	U	U	U	Y	U	U	U	Y	Y	Y	U	U	Y	Y	U
---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---

20. Main outcomes accurate (valid and reliable)?

Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	U	Y	Y
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21. Participants in different conditions recruited from same

Y	Y	U	Y	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
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population?																		
22. Participants in different conditions recruited over same time period?	Y	Y	U	Y	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
23. Participants randomised?	Y	Y	N	Y	Y	N	Y	N	N	Y	Y	N	Y	Y	Y	Y	N	N
24. Randomisation concealed from both participants and staff until recruitment was complete?	U	Y	N	Y	Y	N	Y	N	N	U	U	N	U	Y	Y	N	N	N
25. Adequate adjustment for confounding in the analyses?	Y	Y	N	Y	Y	Y	Y	N	N	Y	Y	N	Y	Y	Y	Y	N	Y
26. Losses of participants to follow-up taken into account?	N	Y	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
27. Sufficient power to detect an effect? (<5% likelihood due to chance)*	N	N	N	Y	Y	N	U	N	N	Y	Y	U	U	Y	Y	U	N	U
Score	20	23	17	25	25	17	24	13	18	22	22	17	22	24	23	22	19	20

*Item has been modified- score as Yes/No/Unable to determine

Table 3 Overview of intervention designs and education components

Overall study content/design	Study authors	Educational delivery methods					Educational content				
		Didactic	Written	Discussion	Interactive	Individual	Dementia knowledge	Delivering care	BPSD	Self-care	Local resources
Educational	<i>Javadpour et al., 2009</i>	X		X	X		X	X	X		
	<i>Kuzu, et al., 2005</i>	X	X	X		X	X	X	X	X	
	<i>Santos et al., 2013</i>	X		X	X		X	X	X		
	<i>Tawfik et al., 2021</i>	X		X	X				X	X	
Therapeutic	<i>Fialho et al., 2012</i>	X		X			X	X		X	
	<i>Senanarong et al., 2004</i>	X		X			X	X	X		
Support	<i>Han et al., 2022</i>	X		X	X		X	X	X	X	
	<i>Zakaria & Ab Razak, 2017</i>	X		X			X	X		X	
Multi-component	<i>Baruah et al., 2021</i>				X		X	X	X	X	
	<i>Dias et al., 2008</i>	X		X		X	X		X		X
	<i>Gavrilova et al., 2009 / Guerra et al., 2011</i>	X				X	X		X		X
	<i>Hinton et al., 2020 / Tran et al., 2022</i>	X	X			X		X	X	X	
	<i>Magteppong & Yamarat, 2021</i>	X	X	X		X	X	X	X	X	
	<i>Pankong et al., 2018</i>	X	X	X	X	X	X	X	X	X	
	<i>Shata et al., 2017</i>	X		X	X		X		X	X	
	<i>Zhang et al., 2020</i>	X	X	X			X	X	X	X	X

3.4. Interventions

Table 3 summarises the interventions' overall design, educational delivery methods and included educational content.

3.4.1. Educational

Four interventions positioned education as their primary focus within delivery (Javadpour et al., 2009; Kuzu et al., 2005; Santos et al., 2013; Tawfik et al., 2021). All the interventions were delivered in person to groups of caregivers. The psychoeducation group (Santos et al., 2013) followed the STAR-Caregivers model (Logsdon et al., 2005) which was a programme initially designed and delivered in the United States of America (USA), where all the other interventions appear to have been independently designed for the LMIC populations in question. All the studies found at least one significant result relating to caregiver mental health or perceived burden. The educative support group study (Javadpour et al., 2009) found significant results on all of the measured outcomes suggesting it is an efficacious intervention. However, the study quality was scored at 13/27, with no control group and a biased sample of only female caregivers which brings into question the validity of these results. Overall, the studies for the educational interventions were scored generally lower in terms of quality. Only one study (Tawfik et al., 2021) had a control group and only one measured intervention adherence (Santos et al., 2013) making it hard to draw firm conclusions on the effectiveness of these interventions.

3.4.2. Therapeutic

Two interventions detailed therapeutic delivery as their focus (Fialho et al., 2012; Senanarong et al., 2004). Both interventions were delivered in person to groups, with adherence to the intervention measured prior to analysis. Significant improvements in caregiver mental health were found in both studies. It is worth noting that in the counselling intervention (Senanarong et al., 2004), the improvement in caregiver mental health was found over time but not between the groups, control and experimental, suggesting that the intervention may not have been a relevant factor in the changes. The Cognitive Behavioural

Therapy (CBT) intervention programme (Fialho et al., 2012) was the only study that found a significant result for a person living with dementia outcome across the whole review, in this case quality of life. The quality of the studies was mixed, with each scoring 17 and 22 (Fialho et al., 2012 & Senanarong et al., 2004 respectively). The CBT programme did not utilise a control group meaning the significant results cannot necessarily be attributed to the experimental intervention.

3.4.3. Support

Two interventions had an overarching focus on support (Han et al., 2022; Zakaria & Ab Razak, 2017). Both interventions were delivered solely within group formats, one was delivered in person and the other via an online forum. The cultural-based support group (Zakaria & Ab Razak, 2017) was based on interventions originally trialled in HICs where the professional facilitated peer support was tailored to delivery in China (Han et al., 2022). The online peer support study found significant results for four out of six measured outcomes relating to mental health and self-efficacy where the support group found one significant result relating to caregiver strain. Neither study utilised a control group and only the cultural-based support group (Zakaria & Ab Razak, 2017) measured adherence, requiring at least 70% intervention completion for the participant scores to be analysed. These design limitations are mirrored in the quality scores for both studies, 17 and 19 (Han et al., 2022 & Zakaria & Ab Razak, 2017 respectively). It is also worth considering that although a high level of engagement for the online peer support form was documented, 85% of participants having reviewed at least 75% of the information on the platform, it cannot be guaranteed how much of this information was read comprehensively. These limitations again mean it is not advisable for the significant results to be taken as definite evidence in favour of these interventions.

3.4.4. Multicomponent

Nine interventions incorporated a range of different components (Baruah et al., 2021; Dias et al., 2008; Gavrilova et al., 2009; Guerra et al., 2011; Hinton et al., 2020; Magteppong

& Yamarat, 2021; Pankong et al., 2018; Shata et al., 2017; Tran et al., 2022; Zhang et al., 2020). These included education, peer support, relaxation techniques, assessment, cognitive strategies, and mood management among other specific elements. Delivery methods varied, four interventions were delivered solely individually, via home visits for three and via an online platform for one. The other five interventions were delivered either solely via group in two studies, or via a mixture of group and individual for the remaining three interventions. The majority of the multicomponent interventions had a general focus but three of the interventions had more specific focusses such as caregiver self-management (Zhang et al., 2020) or enhancing the positive aspects of caregiving (Pankong et al., 2018). Three of the interventions formed part of the wider 10/66 research programme based on the “home care program” and “Helping carers to care” initiative (Dias et al., 2008; Gavrilova et al., 2009; Guerra et al., 2011). The REACH VN multicomponent intervention (Hinton et al., 2020; Tran et al., 2022) was also drawn from a wider research programme, REACH VA (Nichols et al., 2016), which was initially designed for delivery in the USA.

All of the studies found significant results. The multicomponent psychosocial intervention programme (Shata et al., 2017) found significant results for all of the four measured outcomes relating to caregiver mental health, knowledge and burden. The other studies all found one or two significant results on a range of different outcome measures from caregiver health to quality of life.

The study quality for the multicomponent interventions was higher than the other categories, ranging from 20 to 25 out of 27. All of the studies included control groups, however three of the control groups used received a different form of active intervention (Baruah et al., 2021; Hinton et al., 2020; Zhang et al., 2020) which could have interfered with the results. Three of the multicomponent interventions were the only studies to also consider retention and recruitment rates (Baruah et al., 2021; Hinton et al., 2020; Zhang et al., 2020) within the review. Alongside this, another three studies were the only investigations to also consider follow-up of between four- and eight-weeks post-intervention completion

(Magteppong & Yamarat, 2021; Pankong et al., 2018; Shata et al., 2017). Despite this increased quality of study design, only four of the studies measured adherence to the interventions, through number of online lessons completed (Baruah et al., 2021) or attendance to group or individual sessions (Dias et al., 2008; Hinton et al., 2020; Pankong et al., 2018). This again makes it difficult to draw conclusions on the effectiveness of the interventions based on the outcomes, given that participants may not have completed the full intervention.

3.5. Intervention Delivery Characteristics

3.5.1. *Group vs Individual*

There was a variety of intervention delivery styles, with nine being delivered in group settings, four being delivered individually and four using a combination of both. For the interventions that utilised groups, group size ranged from four to 20 participants. Five papers did not document the group sizes at all and three only gave a participant range. An average group size, using absolute group sizes and group range means, was calculated as 7.7 participants per group. One study involved an online forum so technically included an overall group size of 159 but this was not included in the group size calculation due to the difference in delivery style. No clear benefit of a particular group size can be concluded from this review.

In terms of significant results, individual interventions found these only in relation to caregiver perceived burden, approaches to dementia and physical health. In comparison, interventions that utilised group or both group and individual, found significant results relating to different areas of caregiver mental health (anxiety, depression, distress) alongside perceived burden, dementia knowledge, quality of life and other more specific outcomes (e.g., self-efficacy). The study results do not indicate any benefit of using a mixed delivery approach of both group and individual, over solely group delivery.

3.5.2. Intervention Length and Dosage

The overall duration of the interventions ranged from four weeks up to 36 weeks, with all the interventions having more than one session or meeting expected. The most common intervention length was eight weeks (6 studies). The length did not appear to impact how efficacious the intervention was meaning that shorter-term interventions of four to eight weeks were no less effective than those delivered over six months. The two studies that found significant results for all of the measured outcomes (Javadpour et al., 2009; Shata et al., 2017) both utilised eight-week durations, suggesting this is an efficacious length for an intervention. However, the studies were mixed in terms of their quality with one not involving a control group (Javadpour et al., 2009).

It is worth noting that the length of the sessions themselves varied between the interventions from 30 minutes to two hours. Within this the regularity of the sessions also varied, seven interventions reported weekly sessions, one intervention noted fortnightly meetings and one intervention reported sessions every six to eight weeks. Of the remaining interventions, two were delivered online so there was no set attendance or session length, and the other six interventions did not detail this information. The multicomponent psychosocial intervention programme (Shata et al., 2017) which found significant results and had a study quality score of 24/27, employed sessions of 45-60 minutes in length. This suggests that shorter sessions are potentially just as, if not more effective, than the longer sessions of two hours.

Intervention dosage ranged from 2.5 to 39 hours. Two interventions did not detail the session lengths in order to calculate dosage and two interventions were delivered online meaning participants had constant access for the study duration so dosage could not be quantified. Of the studies where dosage could be calculated, the average was 11.4 hours. Most interventions used weekly sessions or visits. One intervention was delivered every 6 to 8 weeks (Senanarong et al., 2004) and no difference was found between the control and experimental groups in terms of caregiver mental health. This suggested that this irregularity

of delivery is less effective than the more commonly used regular weekly delivery. The results also suggest that lowest dosage of 2.5 hours may not be as efficacious, however it is worth noting that the intervention that delivered this dose (Gavrilova et al., 2009; Guerra et al., 2011) was also delivered to individuals, rather than in a group-based format, which may have contributed to these less significant findings. The 39-hour dosage intervention (Santos et al., 2013) was an outlier in terms of intensity and the caregiver outcomes did not indicate this was any more effective than an intervention dosage closer to the average.

3.5.3. *Internet-based vs In-person*

The delivery method utilised varied across the studies. Six of the studies were delivered face-to-face in settings such as hospitals, health clinics or university buildings. Another five studies did not specify the location, but it is assumed by the nature of the intervention, the location, and the year of publication that these interventions also occurred face-to-face in public venues. Of the remaining studies, four were delivered through home-visits and only two were delivered online.

The two interventions that were delivered online, differed in terms of their delivery, with one utilising professional facilitators and a community group (Han et al., 2022) where the other provided an online learning platform where participants self-administered lessons (Baruah et al, 2021). The online iSupport programme (Baruah et al., 2021) found low levels of recruitment and retention documented as 44.67% and 36.42% respectively. It was also calculated that 31% of caregivers completed the recommended five or more lessons, and 45% did not complete any lessons at all. In comparison, the professionally facilitated online peer support found that 85% of participants reviewed at least 75% of the information on the platform and informal feedback also found that 92.4% of the caregivers thought the level of support received was important or very important. Alongside this, the peer support forum study found four significant results relating to caregiver mental health and self-efficacy, where the learning platform study only found a significant result relating to caregiver approaches to dementia despite also measuring mental health and self-efficacy outcomes.

These differences suggest that online delivery is feasible and acceptable to caregivers in LMICs but that the presence of professional facilitators and peer interactions are important for intervention adherence and effectiveness.

3.6. Educational Component

Educational delivery was divided into five categories: didactic, written, discussion, interactive and individualised. Only one study utilised only one form of delivery and only one other utilised all five. The most used were didactic and discussion-based delivery.

Educational content was divided into five categories: dementia knowledge, delivering care, behavioural and psychological symptoms of dementia (BPSD), self-care and local resources. Only one study delivered content on all five areas and all other studies delivered different combinations of two to four content areas.

4. Discussion

4.1. Summary

Eighteen papers, detailing 17 different studies from 11 LMICs, were identified for inclusion within the review. It is somewhat challenging to directly compare the studies and the included interventions due to the differences in designs and measured outcomes, but the explorations within this review have resulted in a few key findings.

Of the 16 different interventions, only four were categorised as having education as their primary focus, where the other 12 either incorporated multiple components including education or had education as a secondary component with a primary focus of peer support or therapy. This highlights the paucity of research in LMICs into caregiver education as a singular intervention component. However, all the studies found at least one significant result indicating that these interventions as a whole do benefit caregivers and are a worthwhile research and public health avenue to pursue.

The studies that investigated interventions that utilised group delivery tended to find significant results for more of the measured outcomes than the interventions that were delivered individually, particularly in relationship to caregiver mental health outcomes. This

finding is supported by previous research that highlighted the value of peer support in wellbeing for caregivers (Dickinson et al., 2017).

Alongside this, the interventions did not appear to become more efficacious as their length increased meaning that shorter term interventions of four to eight weeks were no less effective than those delivered over six months. Similarly, shorter session lengths of 45-60 minutes seemed to be just as beneficial, if not more so, than longer sessions of two hours. In terms of overall intervention dosage, regular weekly or biweekly sessions accumulating to a total average of around 12 hours looked to be the best fit for caregivers and their resulting outcomes. These are important findings to consider given that there is often a lack of public funding and infrastructure in LMICs (Wang et al., 2014) that may prevent more rigorous and long-term interventions, as seen in this review, being implemented. Thus, interventions could be shorter and less intensive and still benefit caregivers to the same degree. This may be particularly relevant given the evidence of lower public awareness and understanding of dementia in LMICS (Shaji et al., 2003) which could mean short interventions, focussing on education, may have greater impact on outcomes than in HICs.

In terms of online delivery, only two of the included studies utilised this approach. This demonstrates that research into this form of intervention is still in its infancy within LMICs. The results of these studies showed potential promise for this delivery method but highlighted the need for professional facilitators and peer support to make it most effective. As such, it is possible online delivery that closely mimics an in-person group can capture the effectiveness of such interventions whilst also allowing for the benefits of using an online platform.

Overall, the multicomponent psychosocial intervention programme trialled by Shata et al. (2017) provides the best example available at present of a high-quality study with promising results in terms of caregiver mental health, burden and knowledge outcomes. The intervention incorporated all of the components that have been shown in this review to be most effective; regular group sessions of around one hour delivered over eight weeks.

Further research would be needed to support this conclusion especially taking into account intervention adherence and feasibility.

Of the 18 studies, only seven reported on intervention adherence, only three reported on feasibility results in terms of recruitment and retention statistics and only three considered follow-ups in terms of outcomes. These points highlight crucial methodological issues as most of these studies were initial investigations. As such, it is important to provide justification for more comprehensive evaluations in terms of clear conclusions and longstanding outcomes (Parker et al., 2008) but also in terms of participant endorsement (Bowen et al., 2009). In addition, none of the studies considered the cost of the intervention and delivery which could also be critical in terms of feasibility when delivering in LMIC contexts with underdeveloped and underfunded services as previously mentioned. This is of notable importance given that although many of these investigations were carried out over five years ago, no further comprehensive investigations or public health implementation of the interventions appear to have taken place. Attention needs to be paid to what is preventing this transition from research to public implementation and whether this is due to the interventions perhaps not being feasible or not being suitable for widespread delivery in LMICs.

4.2. Nature of the Interventions

There appears to be a tendency in the field to investigate a number of different intervention styles including educational, psychotherapeutic, multicomponent and mindfulness based (Cheng et al., 2019). This is challenging for research clarity as these categorisations are arguably ambiguous and rely on subjective researcher decisions especially if limited information is provided on the intervention contents (Walter & Pinquart, 2019). Researchers also make recommendations about delivery methods, for example advising the use of peer groups to increase effectiveness in terms of caregiver psychological wellbeing (Dickinson et al., 2017). However, there is a lack of exploration into the underlying active mechanisms or core components that result in positive outcomes for caregivers and

attention needs to be given to this so that interventions contain the necessary components and avoid any that are redundant.

The variety of interventions being trialled, as captured within this review but also more widely within the field, perhaps demonstrates the diverse needs of caregivers but also the diversity of contexts where delivery is occurring. This underlines the need for research to not only consider the active mechanisms but also focus on the practical implementation of interventions in a range of clinical settings and whether interventions and active mechanisms are universal or culturally specific.

4.3. Education Delivery and Content

There was a range of different educational delivery methods and educational content delivered with the included interventions. The studies lacked coherence in terms of which components were included, and it was not possible to draw conclusions within this review regarding which were most efficacious. Literature mimics this lack of clarity about the most effective means of education delivery with some reviews concluding that individualised support is better (Parker et al., 2008), whilst others highlight the important of group involvement and active participation (Walter & Pinquart, 2019). There appears to be an overarching lack of research into the educational content being delivered and how this can be categorised. This may also be limited by the lack of consistency in how studies report on the intervention contents, with some not giving any details and others providing manuals that can be followed for replications.

Attention perhaps needs to be given to how different researchers and interventions are conceptualising 'education'. Different studies label this as "education", "psychoeducation" or "training" for example, with little discussion in the literature about whether these labels capture the same concept. The lack of clarity around this issue can also be seen in the wide range of outcome measures used to capture results. There are unanswered questions at present as to why interventions include education if the primary focus is on other areas such as quality of life or burden, rather than knowledge. Research to

understand the active mechanisms and content and how these impact different outcomes is needed in order to provide evidence-based rationales for the inclusion of education.

4.4. Clinical Implications and Future Research

Clinically, this review has provided evidence that interventions for caregivers of people living with dementia in LMICs have achieved promising findings in terms of caregiver outcomes and would be worthwhile implementing in public health settings. For example, inclusion of educational content, regularly delivered sessions in groups over shorter time frames in multiple sessions appear to be good options for dementia care in a number of countries.

Moving forwards, , there is a need within the field for more high-quality research, such as RCTs, exploring dementia caregiver interventions in LMICs particularly in terms of dissecting the active components in terms of overall intervention design as well as with regards to educational delivery and content. This will allow for evidence-based designs and rationales for interventions moving forwards. Assumptions about effective interventions must be avoided when drawn from research in HICs until there is an evidence base to support universal active mechanisms of change. There has been a move towards simultaneously developing interventions for both LMICS and HICs (Baker et al., 2022) as this could allow for designs suitable for widespread dissemination.

Further to this, the feasibility of the interventions also needs to be considered in order for the research to progress from academic to clinical implementation. Feasibility should capture recruitment and retention rates but also consider cost-effectiveness of the interventions as this is often neglected within research (Carter et al., 2020). A culturally adaptable Dementia Awareness for Caregivers course template was recently designed (Stoner et al., 2022) that can be delivered to caregivers in LMICs in a one half-day session. Although yet to be formally evaluated, this study provides one of the first examples of a brief intervention for caregivers, which may be more easily disseminated into public health services than the more intensive interventions evaluated in this review. It also provides an

example of an international template that can be adapted for different cultures and populations, where there is potential for both universal and culturally specific active mechanisms to be included when they become more clearly understood.

Feasibility should also be considered in terms of participant endorsement and intervention acceptability. None of the present studies included qualitative evaluations. Qualitative data would allow researchers to understand how caregivers experience interventions, which designs, delivery methods and contents feel most relevant and most likely to lead to change. This could help to illuminate possible active mechanisms of change. In addition, capturing caregiver opinions and priorities for interventions and outcomes could show how they align and diverge from other participant populations but also from researchers. It is not clear at this point whether caregivers prefer education-only interventions or interventions that involved education amongst other components. It would be important to understand these preferences when moving forward with clinical implementation. This would thus allow for more co-produced and adaptable interventions, guided by universal but also culturally specific needs.

The potential benefits of using online and internet-based interventions have started to be explored and referenced within the included studies but also reviews within the field (Christie et al., 2021). However, the limited number of studies using these approaches means conclusions are hard to draw at present. Further exploration is needed into how technology can be utilised in LMICs as access to the right equipment and connectivity is potentially lower than in HICs. On the other hand, these new delivery styles may provide novel ways of reaching rural communities who may have been previously unable to access support, as well as reducing the costs of intervention delivery which could appeal to government funders.

4.5 Limitations

Due to the small number of studies within the area meeting the inclusion criteria, all were included regardless of research quality. Building on this, the Downs and Black quality

appraisal checklist used does not capture all factors and excludes areas such as replicability and feasibility.

It is worth noting that grouping all LMICs together can be considered a limitation as it does not provide scope for the consideration of the wide-ranging differences within these countries in terms of healthcare systems and dementia care. While the current limited amount of research in this field in LMICs may partially justify this categorisation in this case, as Lencucha and Neupane (2022) suggest a more nuanced and targeted approach to categorisation would be worth considering moving forward. Perhaps consideration of countries with and without national dementia strategies, or similar healthcare systems, could be an option for grouping and comparing interventions that have been trialled in future.

Alongside this, an overarching categorisation of a country as a LMIC can be considered limited in terms of the nuances of dementia care within the country itself. For example, it does not provide information of the differences in care within a country between urban and rural areas or whether dementia caregiver interventions are suited universally or to specific areas within a country. Within this, there is also likely to be differences in formal dementia diagnoses within different areas of the same countries and between countries as well. The inclusion criteria within this review of a formal diagnosis dementia may have prevented the inclusion of important research in areas where formal diagnoses are much less prevalent (Ferri & Jacob, 2017). As research in these areas continues to develop, it will be important to pay attention to these differences and consider the clinical realities of diagnosis and intervention delivery within reviews to prevent important data being sidelined due to academic inclusion criteria or categorisations.

The included studies also highlighted the lack of consensus in the research about the outcomes that interventions are expected to impact, with over 40 different outcome measures used. This means that direct comparison of study results is not possible. Consensus is needed within the field about the outcomes being considered and the rationales for this as well as the rationale for why other outcomes are not (Cheng et al.,

2019). Ethically, this is also important as this lack of clarity often leads to poor prioritisation of measures meaning caregivers must complete more questionnaires despite their lack of time and other priorities (Drummond et al., 2019) and may not consider different priorities in terms of outcomes between clinicians and caregivers (Parker et al., 2008).

The review included studies from across the world but did not include any studies not written in English which could potentially mean that important findings from other cultures and settings have not been included. This is important to consider given that the databases searched will only have included abstracts if written in English so other non-English journal abstracts may not have been identified for screening at all. Although the search strategy adopted was as comprehensive as possible given research constraints, it cannot be discounted that grey literature was missed and other literature discounted due to its unavailability.

Additionally, due to the variability in methods and findings, the review was unable to directly compare quantitative findings and as such, results were compared in terms of categories and thematic groupings chosen by the researcher which were reliant on the papers reporting all included content. This process was informed by other reviews in the area that had made similar classifications (Cheng et al., 2019; Gallagher-Thompson et al., 2012) and arguably provides a novel means of intervention comparison where educational delivery and contents have not previously been dissected and compared in this way. However, these groupings are based on somewhat descriptive and subjective choices with Walter and Pinquart (2019) arguing that such categorisations can be ambiguous. It could be worth in future considering the use of established typologies for caregiver interventions such as the framework provided by Davis (1996) grouping interventions based on their main aim from education and skills training to management of affect/stress. Given the variability in study quality and the detail provided in the papers, this review was not able to identify specific primary outcomes within trials and attention was mainly focussed on evaluation of significant findings based on reported *p*-values. There are, however, limitations within this

that cannot be ignored. Greater consideration and comparison of non-significant results would be important in future in order to prevent publication biases being proliferated within reviews (Nair, 2019), and also to encourage the publication of studies with negative results as this is still important research that needs to be disseminated.

5. Conclusion

There is no doubt that interventions for caregivers of people living with dementia in LMICs are needed, and that this need will continue to grow. This review indicates that the inclusion of educational content, delivered regularly within group settings over shorter time frames, in shorter sessions, is promising for caregiver interventions, with a range of significant results found. At present, the multicomponent psychosocial intervention trialled by Shata et al. (2017) provides the best example of this. This research is still in its infancy and further high-quality investigations are needed. It is not possible at this stage to identify the active mechanisms or components in terms of the overall intervention design, the educational delivery methods or the educational content included. Consideration also needs to be given to how education is being conceptualised and measured, the rationale for its inclusion and whether there are universal or culturally specific caregiver needs and outcomes.

The aim of all studies in this field should always be for widespread evidence-based public health implementation which appears not to have been prioritised historically. As such, collaboration between HICs and LMICs, and between researchers and caregivers, is advisable in order to work towards worldwide health equity for dementia with the clinical realities of intervention delivery in terms of outcomes, cost, feasibility and cultural acceptability placed at the forefront.

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Part Two: Empirical Paper

Investigating the Feasibility, Acceptability, and Impact of an Online UK Dementia Awareness for Caregivers Course: A Quantitative Study

Abstract

Background: Informal caregivers are vital in assisting people living with dementia (PLWD). However, this role can significantly impact caregivers and interventions to support them are crucial. This study aimed to develop a United Kingdom (UK) version of the Dementia Awareness for Caregivers (DAC-UK) course and to investigate the feasibility and acceptability of delivering the course online to caregivers of PLWD. The study also explored the possible impact of the DAC-UK course on a range of caregiver outcomes.

Method: The DAC-UK course was developed using the international template alongside stakeholder consultation. Fifty-one participants were randomised into the DAC-UK course or treatment as usual (TAU). Outcomes relating to perceived burden, attitude, competence, relationship quality and positive caregiving aspects were measured at baseline and follow-up, alongside statistics relating to recruitment, retention, attendance, and adherence.

Results: The DAC-UK course appeared to be both feasible and acceptable for caregivers and for further research. The study found high retention and attendance rates with low levels of unexplained attrition. Analysis indicated positive change for four of the outcome measures in favour of the DAC-UK course, however this was not statistically significant.

Conclusion: The DAC-UK course is a promising online intervention for caregivers of PLWD with high feasibility and acceptability. The course provides a novel, brief, and proactive intervention to support caregivers. A larger research trial is needed to reinforce these findings and to further explore the possible impact of the course on caregiver outcomes, prior to public health implementation.

1. Introduction

Nearly a million people have now been diagnosed with dementia in the United Kingdom (UK) (Wittenberg et al., 2019) and this number is continuing to rise. Many of these individuals are cared for by informal caregivers (Gallagher-Thompson et al., 2012), defined as unpaid family, friends, or community members. Estimates suggest that there are approximately 670,000 informal caregivers currently in the UK and they contribute the equivalent economic value of £11 billion and provide over 1.34 billion hours of unpaid care (Prince et al., 2014). As the prevalence of dementia continues to increase, it is estimated that this number will increase to 1.7 million informal caregivers by 2050 (Lewis et al., 2014). Not only do these caregivers limit the wider economic impact of dementia, but they often delay the institutionalisation of individuals with dementia and improve these individuals' physical and mental health (Christie et al., 2021). These statistics highlight the need for dementia care in the UK to involve informal caregivers alongside people living with dementia (PLWD).

It is unsurprising that the caregiving role has a profound impact on the individuals who take it on, given the complexity and progressive nature of dementia as a neurodegenerative disease. Stigma and stereotypes regarding dementia are prevalent in the UK (Alzheimer's Disease International, 2019) which may be due to a lack of public knowledge and education about dementia meaning these beliefs proliferate. Caregivers are at risk of experiencing high levels of burden (Smith et al., 2018), particularly when the PLWD is living in the community (Bleijlevens et al., 2015). This burden can in turn lead to deteriorations in caregivers' physical and mental health (Frias et al., 2020). Alongside this, a robust relationship between dementia caregiving and increases in anxiety and depression has been found (Brodaty & Donkin, 2009) leading to poor mental health outcomes (Black et al., 2013). Evidence suggests that these levels of distress experienced by caregivers also continue to increase over time due to the disease progression (Kannan et al., 2011). As demonstrated, the role of the caregiver is life-changing and can have a significant effect, not

only on them, but also on the person they are caring for. Furthermore, without support, the impact of caregiving can lead to earlier institutionalisation of the person with dementia as well as poorer outcomes for the caregiver themselves (Brodaty & Donkin, 2009).

Despite this undisputedly significant role, at present, there is no standardised policy in the UK regarding support for informal caregivers (NICE, 2018). The UK government launched an initiative in 2015 called the “Dementia 2020 Challenge” aiming to make dementia care in the UK the best in the world (Department of Health, 2015). However, the most recent review of this initiative highlighted that improvements are still needed in terms of the help provided to caregivers (Department of Health, 2019). Qualitative data from UK caregivers reiterates this, with caregivers reporting being left with almost no education on dementia or its progression (Francis & Hanna, 2022). This is in contrast with the World Alzheimer’s Report recommendation for targeted dementia public health campaigns worldwide to mitigate negative outcomes for caregivers (Alzheimer’s Disease International, 2019). At present, interventions are often offered through third sector organisations such as charities or idiosyncratically by local National Health Service (NHS) services.

There is large field of research investigating suitable interventions for caregivers of PLWD, particularly in high-income and Western countries (Drummond et al., 2019), in order to address the current shortcomings in caregiver support. A recent review (Cheng et al., 2019) categorised the different interventions that have been trialled into psychoeducation, counselling and psychotherapy, multi-component and mindfulness based. The interventions categorised as psychoeducational have been found to reduce burden, anxiety, and depression as well as increase caregivers’ quality of life (Frias et al., 2020) and enhance their self-reported ability to care due to a greater understanding of the disease (Kwok et al., 2013). These findings emphasise the importance of public education and awareness of dementia in lessening the impact of the caregiving role.

The Strategies for Relatives (START) programme is one example of an educational intervention, piloted in the UK, which has been found to be both clinically and cost-effective

for a UK caregiver population (Livingston et al., 2014; Livingston et al., 2020). However, the manualised programme is designed to be delivered over eight sessions meaning the intervention can be classified as longer-term as it requires caregivers to commit to multiple session attendances. There appears to be fewer examples of shorter-term or one-off, brief interventions that have a similar preventative or proactive focus, thus aiming to avoid caregivers reaching burnout or experiencing negative outcomes. Further to this, a brief or single session educational intervention for caregivers would require less resources, less professional commitment and lower financial investment making it even more plausible for the UK government to consider implementing through the NHS (Christie et al., 2021).

Aligning with this, an internationally adaptable Dementia Awareness for Caregivers (DAC) course template has been designed for delivery to informal caregivers (Stoner et al., 2022). The course is designed to provide brief, accessible, and culturally valid educational information within a one-off half-day session. The DAC course template was initially designed through the support of diverse stakeholders, before being adapted and trialled in India, Brazil, and Tanzania. Participant feedback has indicated acceptability of course content, with respondents noting the value of both practical information and psychological principles. This feedback was in conjunction with high levels of delivery feasibility and retention rates. The adaptability of this template is important when considering the diverse cultures and communities with the UK where tailored interventions could be beneficial.

The initial field tests for the DAC course were delivered in person. However, given the ongoing COVID-19 pandemic and the resulting transition in many services to using online means of patient support (Giebel et al., 2021), the DAC course could also be reasonably adapted for online delivery. Online caregiver forums have been found to be effective in supporting individuals and improving caregiver-PLWD relationships (Carter et al., 2020) indicating online platforms are valuable tools to consider. This is especially relevant within this service user group as caregivers often cannot leave the PLWD alone or have health or mobility issues that can make attending face-to-face interventions challenging (Dai et al.,

2020). In addition, given the economic climate and often reducing service funds, online options are definitely worthy of further investigation. Therefore, this study aimed to develop and deliver an online DAC-UK course in order to explore the intervention's impact and whether it could provide a feasible and acceptable option for delivery to informal UK caregivers within a public health context. The main aims were:

1. To adapt the international DAC course template thus creating a UK version of the course (DAC-UK).
2. To evaluate the feasibility and acceptability of the online DAC-UK course.
3. To assess the possible impact of the DAC-UK course on caregiver outcomes.

2. Method

2.1. Design

A mixed methods pre-/post-intervention parallel group design was used to assess the feasibility and acceptability of the DAC-UK course and to explore possible caregiver outcomes. The trial comprised of two conditions to which participants were randomly allocated on a 1:1 basis; the treatment condition that received the DAC-UK course and the control condition of treatment as usual (TAU) meaning the participants were not offered an active intervention within the trial but were able to access their normal services outside of the study. Participants in the treatment condition were also able to continue accessing their usual support outside of the study.

This was a joint research project conducted with Ria Patel (Trainee Clinical Psychologist). This paper reports on the quantitative results in terms of feasibility, acceptability, and outcome measures. Ria Patel will report on the qualitative acceptability and feedback from caregivers following course attendance (see Appendix 2). This paper will reference Ria's contributions or ownership over parts of the study with the initials RP.

2.2. Ethical Approval

Ethical approval was obtained from the University College London Research Ethics Committee (Project ID: 22375.001, see Appendix 3) by both researchers (RP/IE). Informed consent (see Appendix 4) was gained from all participants prior to participation. The participants were informed they could withdraw at any point during the study prior to data analysis, without having to give a reason.

2.3. Participants

The participants were informal caregivers of PLWD in the UK. Informal caregivers were defined in this study as family members or friends providing unpaid care to the PLWD.

Inclusion criteria:

- Self-identified informal caregiver of a person living with dementia in the community.
- Residing in the UK.
- Ability to engage in a course delivered in English.
- Have access to an internet-connected device capable of videoconferencing (camera and microphone functioning).
- Available to attend pre-specified dates for DAC-UK course delivery.

Exclusion criteria:

- PLWD residing in residential care.
- Professional caregiver of PLWD.

Participants were recruited from four different research bases across the four countries in the UK: England, Wales, Scotland, and Northern Ireland, with one research base randomly selected for each country according to the recruitment website list.

Recruitment was carried out using the Join Dementia Research (JDR) website where researchers can advertise their studies and recruit caregivers of PLWD (Join Dementia Research, n.d.). The advert provided on the JDR website included study details, inclusion criteria and a study poster (see Appendix 5). Potential participants were provided with an

information sheet (see Appendix 6) via an emailed link (see Appendix 7) to a Qualtrics (an online survey platform) page which then led to the consent form if they wished to participate (see Appendix 4). Recruitment was carried out between June and August 2022 by both researchers (IE/RP).

As the study was an initial feasibility trial, the sample size was not powered to detect a clinically significant effect. A sample size of 50-60 participants was selected in alignment with research recommendations for feasibility studies (Browne, 1995; Sim & Lewis, 2012). This sample size also allowed for possible attrition and subsequent participant ineligibility.

2.4. Intervention – Dementia Awareness for Caregivers (DAC) Course

The DAC course international template was developed iteratively, with stakeholder involvement from dementia care professionals and informal caregivers who provided patient and public involvement (PPI). This was completed as part of the ongoing Cognitive Stimulation Therapy (CST) International project, which is a Medical Research Council (MRC) funded research programme, that included the DAC course development and field testing in Brazil, India and Tanzania. The course comprises of three modules: What is Dementia, Positive Engagement and Caring for Someone with Dementia. It was designed to be delivered to a small group of caregivers in one session lasting between three and four hours. The original field testing of the DAC course was carried out in person, whereas in this study the course was adapted for online video-conference delivery. There is also research currently being written up which investigated the online delivery of the DAC course in both Brazil and India, which aligns well with this study. Table 1 presents a detailed breakdown of the course content, interactive components, and resources provided to caregivers. Further information on the specific course content can be found in the original DAC course paper (Stoner et al., 2022).

2.5. Adaptation of DAC Course for the UK

The DAC-UK course was developed by adapting the original DAC course template (Stoner et al., 2022). Adaptations were made by the research team (IE/RP) in terms of

country specific information such as medication access via prescriptions on the NHS, available services through charities and third sector organisations, and statistics relating to dementia prevalence in the UK. The course was also updated to include culturally relevant myths about dementia, examples, and exercise content that caregivers could relate to. For example, considering the steps involved in making a cup of tea and myths around dementia being a normal part of ageing. This process was guided by the course manual document and PowerPoint slides provided (for further detail on the adaptation process, see Stoner et al., 2022) . Six stakeholders, recruited through researcher personal links (IE/RP), were contacted via email for their feedback on the DAC-UK course: two PLWD, two informal caregivers and two professional caregivers. Each stakeholder was asked the same questions relating to the areas of the course that had been adapted:

1. Is there anything you feel needs to be improved?
2. Do you think we have missed anything important or need to take out of the course?
3. With regards to the slide on “common myths” – are these in line with what you have heard/experienced? Do you think we need to add any others?

The stakeholders were reimbursed for their time with a £10 retail voucher.

Table 1*Overview of the Dementia Awareness for Caregivers Course*

Modules	Time allocated (approximate)	Content	Interactive activities	Resources provided
Welcome/Introduction	10 minutes	<ul style="list-style-type: none"> - Housekeeping/group rules - Course content overview 	<ul style="list-style-type: none"> - Welcome activity – introductions and hopes 	
What is dementia?	30 minutes	<ul style="list-style-type: none"> - Dementia statistics - Myths and facts - Types of dementia - Progression of dementia - Understanding dementia - Biopsychosocial model 	<ul style="list-style-type: none"> - Group discussion – current knowledge and community understanding - Activity – steps in making a cup of tea 	<ul style="list-style-type: none"> - Links and contact details provided for dementia information
Positive engagement	90 minutes	<ul style="list-style-type: none"> - Personhood - Malignant social psychology - Positive person work - Positive engagement - Psychological needs - Stimulating and exercising the brain 	<ul style="list-style-type: none"> - Case study and discussion – examples of malignant social psychology - Reflection and discussion – meeting PLWD* needs. - Discussion – using positive person work - Discussion – exercising the brain ideas 	<ul style="list-style-type: none"> - Malignant social psychology examples - Positive person work examples
Caring for someone with dementia	30 minutes	<ul style="list-style-type: none"> - Nutrition and hydration - Activities of daily living - Stress and distress - Risk management - Medication - Non-drug treatments - Impact of caring - Caregiver needs - Services for PLWD* - Services for caregivers 	<ul style="list-style-type: none"> - Discussion – ideas for adjustments to ‘activities of daily living’ - Questions 	<ul style="list-style-type: none"> - Activities of daily living table - Behavioural chart - Positive and negative aspects of caregiving table - Signposting for caregiver support - Signposting for PLWD* support

*PLWD = person living with dementia

2.6. Procedure

All volunteers who expressed an interest in taking part in the study were screened by the researchers prior to being provided with the consent form. Once informed consent was obtained, participants provided a unique code for randomisation and data collection. All participants were randomly allocated, on a 1:1 basis, into either the treatment condition (DAC-UK course) or the control condition (TAU) by the researchers (IE/RP), using online randomisation software (Random Lists, n.d.). Those in the DAC-UK course condition were allocated into three groups of between six and ten participants. In the week prior to the delivery of the DAC-UK course, all participants from both conditions, were emailed (by RP/IE) and asked to complete an online questionnaire comprising of demographics information questions (see Appendix 8) and the five outcome measures (see below). Completion of baseline measures at this point was pragmatic and in line with the research protocol for the DAC course trials in Tanzania and India.

Following this, the treatment condition groups participated in the half-day (3-4 hour) DAC-UK course whilst the control condition continued with TAU. All the courses were delivered within three months of recruitment and participants were provided with the relevant dates within the recruitment email. The DAC-UK course was delivered online via videoconferencing software 'Microsoft Teams' and facilitated by one of the researchers (IE/RP). One month after the DAC-UK course delivery, both conditions completed the same five outcome measures. The DAC-UK course condition groups also took part in 30-minute individual online interviews (via Microsoft Teams). Each interview was facilitated by the researcher that did not facilitate the course the participant had attended (RP/IE) in order to reduce the likelihood of biased interviews. All participants were sent or had online access to an end of participant information sheet with contact details for further support and helpful organisations (see Appendix 9).

In the initial round of the trial, the DAC-UK course was run three times (delivered twice by IE and once by RP). Due to several participants not attending or having to cancel

attendance at short notice, another fourth course date was offered to these participants (delivered by IE). The same procedure in terms of measure completion and interviews was followed.

2.7. Outcome Measures

2.7.1. Primary – Feasibility and Acceptability

The present study assessed whether the DAC-UK course could be feasibly delivered as an online course for caregivers, whether it would be feasible to test in a research trial and whether it was acceptable to those participating in it. Only quantitative measures of feasibility and acceptability are reported in this study (qualitative measures are included in the report by RP). This was measured through recruitment and retention rates, intervention attendance and adherence alongside outcome measure completion rates.

For the purposes of the current study, the DAC-UK course was considered feasible if recruitment of the target sample was successful within six months and if there was a retention rate of at least 75% of participants at follow-up. The intervention was considered acceptable if overall attendance and retention rates of the caregivers were over 60% and completion of the outcome measures was higher than 75%. This aligns with thresholds set in other feasibility and acceptability studies (Blok et al., 2018; Galea et al., 2021).

2.7.2. Secondary – Quantitative Outcome Measures

Although this study was not powered, all of the participants completed the same battery of five questionnaires at baseline and follow-up. This allowed for the exploration of the impact of the intervention on these outcomes and whether it would be worth measuring them moving forwards. The measures were administered via Qualtrics, an online survey platform, with participants completing them independently.

Caregiver Competence. The Short Sense of Competence Questionnaire (SSCQ) (Vernooij-Dassen et al., 1999) is a 7-item questionnaire that measures an individual's sense of competence in their role as a caregiver (see Appendix 10). Each item is scored on a five-

point Likert scale from 1 to 5, where 1 is agree strongly and 5 is disagree strongly. Scores can range from 7 to 35 with higher scores indicating a greater sense of competence/satisfaction. The SSCQ has been found to have high construct validity ($r=0.88$) when compared to the original sense of competence questionnaire and alongside this, high reliability ($\alpha=0.76$) (Vernooij-Dassen et al., 1999).

Caregiver Approach to Caregiving. The Approaches to Dementia Questionnaire (ADQ-19) (Lintern., 2001) is a 19-question survey that measures an individual's attitudes towards dementia and PLWD (see Appendix 11). Each question is scored on a five-point Likert scale from 0 (strongly agree) to 4 (strongly disagree). Reverse scoring is used on items 5, 7, 9, 11, 12, 15, 16, 17, 18, 19, and an overall high score indicates positive attitudes towards dementia and PLWD. The ADQ-19 has been shown to have good reliability ($\alpha=0.76$ for hope, $\alpha=0.85$ for person-centredness) and validity when compared with similar measures and qualitative observations (Lintern., 2001).

Caregiver Burden. The short-form Zarit Burden Inventory (ZBI) (Zarit et al., 1980) is a 12-item questionnaire that measures caregiver's perceived burden as a result of their role (see Appendix 12). Each item is scored from 0 (never) to 4 (nearly always) where a low score is indicative of a low sense of burden. The ZBI is one of the most commonly used measures for burden in the field (Carter et al., 2020) and has been shown to have high levels of validity and reliability (Higginson et al., 2010).

Quality of Caregiver and Patient Relationship. The carer version of the Quality of the Caregiver Patient Relationships (QCPR) (Spruytte et al., 2002) is a 14-question survey that captures the positive and negative aspects of the caregiving relationship (see Appendix 13). The questions are scored on a 5-point Likert scale where 1 is totally disagree and 5 is totally agree. Six items are reversed scored (2, 3, 8, 10, 11, 13). A score of less than 42 is considered indicative of a poor caregiver-patient relationship, a score of 42-56 is labelled as a standard relationship, with scores of higher than 56 indicating a good relationship. Reliability and validity of the QCPR have been found to be high (Spruytte et al., 2002).

Positive Aspects of Caregiving. The Gain in Alzheimer's care instrument (GAIN) (Yap, 2010) comprises of 10 questions that cover the possible positive aspects of a caregiving role in terms of the relationship with the PLWD, self-reflection, and personal development (see Appendix 14). Each question is scored from 0 to 5 (disagree a lot to agree a lot) where a high score suggests a high level of positive gain from caregiving. This tool has been found to be valid and reliable for use (Yap, 2010).

2.8. Data Analysis

Independent samples t-tests for the five outcome measures were carried out to ascertain that the two groups were not significantly different at baseline. Demographics data were computed at baseline in terms of descriptive statistics.

Pre- post- change scores were calculated, for each participant, for each of the five outcome measures. These scores were then analysed via a between-subjects multivariate analysis of variance (MANOVA) comparing the two conditions. Separate between-subject univariate ANOVAs were also carried out for each of the outcome measures to further the exploratory analysis. All quantitative analysis was carried out by the author (IE).

3. Results

3.1. Adaptation of DAC Course for the UK

The six stakeholders who were contacted for their feedback on the DAC-UK course: two PLWD, two informal caregivers and two professional caregivers, provided email feedback on the intervention (see Appendix 15). All of the stakeholders reported that the information included in the course felt relevant and useful. One professional caregiver noted that it would be worth adding in more information on the different types of dementia and details about the impact of dementia on physical mobility. This was added by the researchers to the course manual. The two informal caregivers and the two PLWD also gave feedback that the course looked to be very useful for caregivers and they or their family would have benefited from being able to attend the course. Following this feedback, the

DAC-UK was sent to the original DAC course author (supervisor CS) who approved it for delivery following the adaptation of an infographic, which was also changed to include further information about physical mobility changes as detailed in the stakeholder feedback (adapted by IE).

3.2. Main Study – Outcomes

3.2.1. Primary - Feasibility and Acceptability

Recruitment and Retention. Please see Figure 1 for flow of participants through the trial. Sixty people expressed interest in taking part in the study following contact from the researchers via email. Nine people (15%) did not meet the eligibility criteria to take part meaning that 51 participants were recruited to take part in the study (85%) within a three-month period. The participants were randomised into the experimental (26 participants) and control (25 participants) conditions.

Of the 26 participants allocated to the DAC-UK course condition, two (7.69%) were no longer eligible to attend the course due to a change in circumstances between consent and course delivery. These changes included the PLWD moving into residential care or passing away. Another participant (3.85%) withdrew from the study citing caring needs. Of the remaining 23 eligible participants, all were invited to attend the course, with 12 (46.15%) invited on two different occasions due to participants being unable to attend the first date at short notice due to work changes, other commitments, or caring needs. The researchers introduced telephone calls confirming attendance and regular reminder emails for the second, third and fourth courses, following the number of cancellations for the first course. This led to greater attendance and fewer cancellations for the courses. Fifteen participants (57.69%) attended the online course, with all of these participants completing both the baseline and follow-up measures. There were four (15.38%) caregivers who did not attend without providing a reason and did not respond when contacted by the researchers following this. The remaining four (15.38%) participants did not attend the group but contacted the

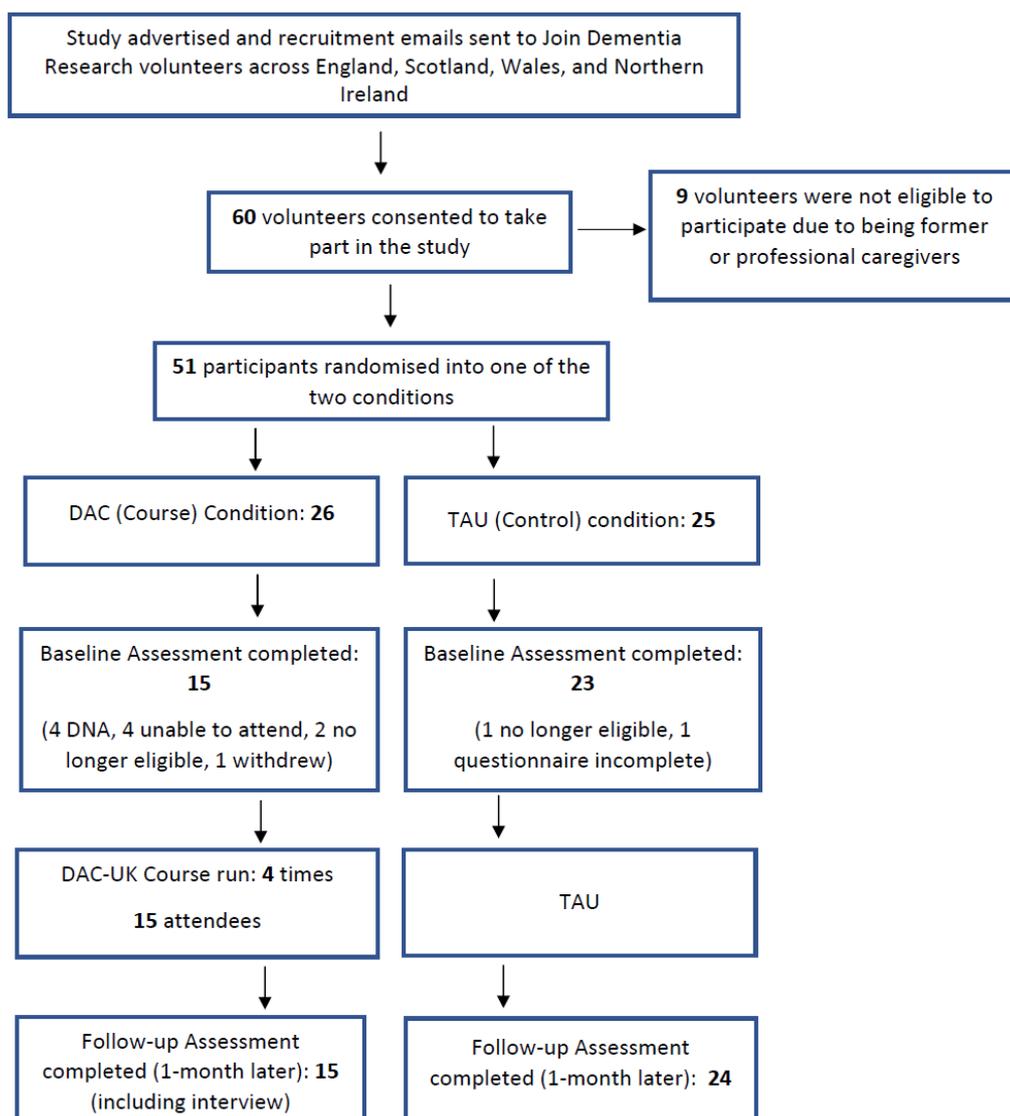
researchers prior to delivery with three referencing work commitments and the other citing health problems.

In the control questionnaire condition, 23 participants (92%) fully completed the baseline measures, of which all were retained by the follow-up assessment. One participant was no longer eligible as they were no longer a caregiver, and the other participant did not fully complete the questionnaires at baseline.

Overall, of the 51 randomised participants, 39 (76.47%) were retained and completed follow-up assessments and interviews where applicable.

Figure 1

Study Recruitment and Retention Flowchart



Attendance and Adherence. Fifteen out of the 26 (57.69%) participants in the treatment condition attended the DAC-UK course. Of these 15 participants, 14 (93.3%) completed the full course and one completed the first two modules but then had to leave due to a personal appointment.

Feasibility of Outcome Measures. Both the SSCQ and the ADQ-19 measures had 100% completion rates with no missing data on either. The three other outcome measures, the ZBI, the QCPR and the GAIN, had a completion rate of 97.44% at baseline and 100% at follow-up.

3.2.2. Secondary – Quantitative Outcome Measures

Analysis was conducted only for the participants who completed both the baseline and follow-up questionnaires.

Demographics. Basic demographics for both the experimental group and the control group are summarised in Table 2.

Table 2
Participant Demographics

Characteristics	All participants (n=39)	DAC-UK (n=15)	TAU (n=24)
<i>Age (years)</i>			
Mean (SD)	60.56 (10.87)	61.80 (8.79)	59.79 (12.11)
Range	32 - 86	46 - 81	32 - 86
<i>Gender</i>			
Female (%)	29 (74.36)	12 (80)	17 (70.83)
Male (%)	10 (25.64)	3 (20)	7 (29.17)
<i>Ethnicity</i>			
White British (including Welsh/Scottish/English) (%)	39 (100)	15 (100)	24 (100)

Characteristics	All participants (n=39)	DAC-UK (n=15)	TAU (n=24)
<i>Marital Status</i>			
Married (%)	26 (66.67)	10 (66.67)	16 (66.67)
Single (%)	4 (10.26)	3 (20)	1 (4.17)
Living with Partner (%)	7 (17.95)	1 (6.67)	6 (25)
Separated (%)	1 (2.56)	1 (6.67)	0 (0)
Divorced (%)	1 (2.56)	0 (0)	1 (4.17)
<i>Education</i>			
Completed Secondary (%)	5 (12.82)	2 (13.33)	3 (12.50)
Completed Tertiary (%)	21 (53.85)	8 (53.33)	13 (54.17)
Completed further education (bachelor's degree/Master's degree) (%)	13 (33.34)	5 (33.33)	8 (33.33)
<i>Relation to PLWD</i>			
Child (%)	17 (43.59)	8 (53.33)	9 (37.50)
Spouse (%)	14 (35.90)	5 (33.33)	9 (37.50)
Son-in-law/daughter-in-law (%)	1 (2.56)	1 (6.67)	0 (0)
Other relative (%)	7 (17.95)	1 (6.67)	6 (25)
<i>Living with the PLWD?</i>			
Yes (%)	17 (43.59)	7 (46.67)	10 (41.67)
No (%)	22 (56.41)	8 (53.33)	14 (58.33)
<i>Caring for anyone else?</i>			
Yes- Child(ren) (%)	8 (20.51)	4 (26.67)	4 (16.67)
Yes – other adult(s) (%)	9 (23.08)	1 (6.67)	8 (33.33)
No (%)	22 (56.41)	10 (66.67)	12 (50)
<i>How many other caregivers involved in the PLWD care?</i>			
0 (%)	4 (10.26)	2 (13.33)	2 (8.33)
1 (%)	11 (28.21)	5 (33.33)	6 (25)
2 (%)	6 (15.38)	2 (13.33)	4 (16.67)
3 (%)	7 (17.95)	3 (20)	4 (16.67)
4 or more (%)	11 (28.21)	3 (20)	8 (33.33)
<i>Level of contribution (%)</i>			
1-20 (%)	9 (23.08)	2 (13.33)	7 (29.17)
21-40 (%)	8 (20.51)	3 (20)	5 (20.83)
41-60 (%)	2 (5.13)	1 (6.67)	1 (4.17)
61-80 (%)	3 (7.69)	1 (6.67)	2 (8.33)
81-100 (%)	17 (43.59)	8 (53.33)	9 (37.50)

Independent samples *t*-tests were completed to check whether the two conditions were significantly different at baseline. The results indicated that the average baseline scores for the five measures did not differ significantly between the groups ($p > .05$) (see Table 3).

Table 3

Baseline Independent Samples T-tests

Outcome Measure	Experimental Condition (DAC) (n=15)	Control Condition (TAU) (n=23)	Independent samples <i>t</i> - test
	Baseline Score Mean (SD)	Baseline Score Mean (SD)	
ADQ-19	73.33 (7.92)	69.96 (8.43)	$t(36) = 1.235, p = .225$
GAIN	26.00 (8.19)	27.96 (6.86)	$t(36) = -0.796, p = .431$
QCPR	49.73 (7.94)	51.52 (8.72)	$t(36) = -0.639, p = .527$
SSCQ	22.80 (4.93)	23.61 (5.19)	$t(36) = -0.479, p = .635$
ZBI	25.40 (7.31)	20.57 (7.64)	$t(36) = 1.939, p = .060$

Note: Higher scores are positive for all measures bar the ZBI where lower scores are positive.

Using Pillai's trace, there was no significant effect of treatment condition on the pre-post change scores (difference in participant score between baseline and follow-up) for any of the five outcome measures within the MANOVA, $V = 0.07, F(5,32) = 0.49, p = .783$. There were non-significant positive changes in the pre-post change score means in favour of the DAC-UK course, compared to TAU, for the ADQ-19, the GAIN, the SSCQ and the ZBI. Follow-up score means and pre-post change score means for the conditions alongside separate univariate ANOVAs, for the between-subject effects, for each of the outcome measures are presented in Table 4. Due to the violation of the assumption of homogeneity of variances in the data, Pillai's trace criterion was used.

Table 4*Within-subject Means and Between-subjects Effects at Follow-up*

Outcome Measure	Experimental Condition (DAC-UK course) (n=15)		Control Condition (TAU) (n=23)		Between-subject Effects
	Follow-up Score Mean (SD)	Pre-Post-Change Score Mean (SD)	Follow-up Score Mean (SD)	Pre-Post-Change Score Mean (SD)	
ADQ-19	75.27 (7.03)	1.93 (5.91)	71.09 (8.28)	1.13 (4.70)	$F(1, 36) = 0.22, p = .65$
GAIN	28.00 (6.80)	2.00 (5.87)	28.57 (6.70)	0.61 (3.26)	$F(1, 36) = 0.88, p = .35$
QCPR	46.33 (8.28)	-3.40 (4.64)	48.48 (8.30)	-3.04 (13.30)	$F(1, 36) = 0.01, p = .92$
SSCQ	23.73 (4.50)	0.93 (3.20)	23.39 (5.36)	-0.22 (3.78)	$F(1, 36) = 0.95, p = .34$
ZBI	24.53 (6.77)	-0.87 (4.19)	21.35 (7.88)	0.78 (5.41)	$F(1, 36) = 1.00, p = .32$

Note: Higher scores are positive for all measures bar the ZBI where lower scores are positive.

4. Discussion

4.1. Summary

This study aimed to create a UK version of the international Dementia Awareness for Caregivers course template and investigate the feasibility and acceptability of the DAC-UK course. It also aimed to explore the possible impact of the course on five different caregiver outcomes.

The current study indicates that the DAC-UK course, delivered online, is both feasible and acceptable to caregivers across the UK and that it is also feasible to be evaluated within a research setting. Despite this, at present, there is no initial evidence found for the impact of the DAC-UK course on caregiver outcomes; perceived burden, approaches to dementia, sense of competence, quality of relationship with PLWD or positive gains from caregiving, although there were some promising non-significant changes. This may be due to limiting factors in terms of the sample size and make-up.

4.2. Feasibility and Acceptability

Based on the criteria established at the beginning of this study, the DAC-UK course appears to be in the most part feasible and acceptable as an intervention for caregivers of PLWD, with some limitations in terms of attendance.

Recruitment of the sample was achieved within half of the pre-set six-month time frame and 76.5% of the participants were retained at follow-up, surpassing the pre-set 75% threshold. The five outcome measures were also shown to be highly acceptable with completion rates of between 97% and 100% across both of the conditions. This suggests that investigating the DAC-UK course, and utilising randomisation, in a research trial context is both feasible and worthwhile.

In terms of the intervention's feasibility, it is worth noting that only 57.7% of the caregivers in the treatment condition attended the DAC-UK course which is below the feasibility threshold of 75%. However, 15.4% of the participants in this condition stated that they were unable to attend the course due to legitimate reasons such as work commitments and health concerns, alerting the researchers to this prior to the course date. It is likely, although cannot be guaranteed, that they would have attended had there been another course date or time available. This means that 73.1% of the participants in the DAC-UK course condition were engaged and willing to participate, a statistic closer to the pre-set threshold although still below, but that potentially the limitations of the research study prevented their engagement.

With regards to intervention acceptability, 93% of the participants who attended the DAC-UK course completed the full intervention and 100% were retained at follow-up indicating a very high level of course acceptability and participant engagement. There was only one participant who did not complete the full course, and this was due to a pre-arranged medical appointment. This level of feedback and participant engagement is higher than was

documented in the original DAC course investigations where in Brazil, only 62% of course attendees gave feedback although it is important to note that this feedback was provided voluntarily by the caregivers (Stoner et al., 2022). Further to this, this also indicates the benefit of a one-off brief intervention in ensuring caregiver adherence to the complete intervention. This is in contrast with multi-session interventions, such as the START programme where only 75% of the caregivers attended five out of the eight sessions (Livingston et al., 2014).

4.3. Caregiver Outcomes

The present study did not find any preliminary evidence that the online DAC-UK course has a significant impact on outcome measures relating to caregiver perceived burden, approaches to dementia, sense of competence, relationship quality with the PLWD or perception of positive gains from caregiving. There were, however, non-significant changes in favour of the DAC-UK course for burden, approaches to dementia, sense of competence and positive gains from caregiving, which would be worthy of further exploration.

As an unpowered feasibility trial, this study only recruited a small sample with the primary aim of evaluating the feasibility and acceptability of the course. This means that the study was not suitably powered and as such, it is less likely to have been able to detect an effect (Button et al., 2013). Further factors that need to be considered in explaining these findings are discussed within the study limitations.

4.4. Strengths and Limitations

This study presents interesting and new findings for the DAC-UK course, with a number of strengths identified. Firstly, the course was developed based on the original DAC course template which was extensively researched throughout the development process and had already been found to be feasible and acceptable in a number of different caregiver populations (Stoner et al., 2022). The development of the DAC-UK course also included further stakeholder consultation which is crucial when developing new interventions as it can highlight to researchers areas to prioritise and any potential issues that may have been

overlooked (O’Cathain et al., 2019). The course was also delivered to caregivers across the UK in order to increase the generalisability of the findings to a wider UK audience, with the possibility of public health implementation held at the forefront of this decision.

However, attention must also be given to the several limitations of the present study. Following randomisation, participants were informed of their condition allocation prior to their baseline measures being collected. This may have introduced bias into the data as the participants’ knowledge of their allocation may have impacted on their performance on the measures (Karanicolas et al., 2010). This methodology was in alignment with the study protocol for the DAC course in India, Tanzania, and Brazil, which required people to complete measures on the day of the face-to-face course for pragmatic reasons. Of note, there was no statistical difference in the two group populations at baseline. Further, high levels of retention for baseline measurement suggests that this did not impact the data within this study. However, the researcher would recommend that it would be more appropriate in future studies or RCTs for the baseline measures to be collected prior to randomisation and group allocation as seen more standardly in other studies in the field (for example, Livingston et al., 2014).

Alongside this, the included demographics questionnaire was also taken from the initial DAC course study in Brazil, India, and Tanzania and although extensive, may have been more appropriate for the populations in Tanzania, India, and Brazil. It would be worth considering the addition of questions regarding participant employment status that could impact their outcome measure scores and how feasible the DAC-UK course would be for them. This could be developed and included in future larger trials of the course in the UK.

In addition, although the sample comprised of an expected range of caregiver ages, genders, and locations, all of the caregivers who participated identified their ethnicity as white. This is not representative of the diverse UK population (Office for National Statistics, 2021) and means the findings are difficult to generalise to caregivers from other ethnic backgrounds. This is a limitation that has previously been noted and associated with using

the JDR platform for recruitment (Perkins, 2021). The different research bases in each of the four UK countries were randomly selected as part of this study in order to prevent researcher bias. Perhaps purposeful selection of different areas to capture diverse participant populations via JDR could have mitigated this issue. Doing so could have allowed for selection of different populations from rural, urban, or areas of economic deprivation for example. This is a technique that has been used in other trials in the field to good effect (Livingston et al, 2014).

Further to this, recruitment via the JDR platform also means the sample was likely comprised of caregivers who may have already undergone supportive interventions in other research initiatives and who were already educated on dementia and caregiving by nature of their interest in volunteering for further research. The sample, therefore, may be less impacted by the DAC-UK course than others. Moreover, anecdotally it appeared that caregivers who volunteer through JDR are often further along in their journey as a caregiver and the PLWD is often towards the later stages of the dementia, perhaps due to signing up to JDR years previously or having taken several years to become aware of the platform. This limitation also meant that a number of volunteers contacted were no longer caregivers but remained on the database. This means that the ideas and concepts within the DAC-UK course may no longer be as relevant and could therefore have less of an impact on caregiver outcomes than if it was delivered to a caregiver soon after the PLWD's diagnosis. Therefore, if the sample had been taken from a diverse caregiver population at the start of their journey, the likelihood of being able to detect effects would likely be significantly greater and the effects would also be more valid. Recruitment via NHS memory clinics or through third sector organisations or charities from across the UK could provide more effective means of recruiting more diverse, eager, and representative participant samples.

The delivery of the DAC-UK course online and recruitment via an online platform may also have biased the sample to caregivers who are more computer literate and potentially made the study inaccessible to other caregivers who could have attended in-person. Given

the ongoing COVID-19 pandemic at the time of recruitment, this was an appropriate delivery method but potentially also limits the ecological validity of the findings.

Delivery of the course was also completed by the researchers, and it cannot be discounted that this may have impacted participant scores following the course due to social desirability bias. Given the small-scale research project, this was unavailable within the pragmatic method design however, in larger scale research having facilitators that are external to the research would be worth pursuing in order to make the data collected as valid and reliable as possible.

Perhaps the most notable limitation of this study was the participants not being able to attend the DAC-UK course, most often due to practical reasons. By nature of the intensity of the informal caregiving role, often falling alongside full-time work and other family commitments, flexibility is crucial when offering supportive interventions. However, given the small-scale research context, there were limited dates available for the course to be run. This is a difficulty that has been found in other smaller research projects within the field (Santos et al., 2013). This constraint is likely in contrast with how the course would be delivered if it was implemented in a public health setting, or a large-scale research project, with more regular and variable times available for caregivers to choose from, meaning that attendance would likely be significantly higher.

4.5. Implications for Future Research

This study provides initial findings that indicate further research into the DAC-UK course is both worthwhile and warranted. A larger randomised control trial (RCT) would be needed in order to further establish the acceptability and feasibility of the DAC-UK course. Consideration within this research needs to be given to the means of course delivery whether delivered via online video-conferencing or in-person. These methods will need to be compared and evaluated for feasibility, acceptability, and impact as both hold value for future public health dissemination, potentially targeting different caregiver populations. Included within this would be research with larger sample sizes, caregivers from different minority

and/or cultural groups and caregivers at different time points in terms of the PLWD's diagnosis and their journey as a caregiver.

In addition, an RCT would provide an opportunity to formally evaluate the cost-effectiveness of the DAC-UK course, especially as intervention cost is often neglected within research (Carter et al., 2020). It is likely that the course would be very low-cost due to its brief, one-off delivery with materials that have already been developed. Formal support of this hypothesis would provide further evidence of the feasibility of the DAC-UK course especially in terms of linking with public health implementation.

It is also worth considering that the outcome measures selected for the current study were based on those selected within the original course development (Stoner et al., 2022). However, there were a number of caregiver outcomes that have been shown to improve following educational interventions (Gallagher-Thompson et al., 2012; Walter & Pinquart, 2019) that were not measured such as mental health outcomes including anxiety and depression, caregiver quality of life and knowledge regarding dementia. Given that the DAC course has a strong focus on psychoeducation, it may be considered more appropriate to include a knowledge questionnaire such as the Dementia Knowledge Assessment (Annear et al, 2017). Thus, further consideration and exploration into possible caregiver outcomes that may be impacted by the DAC-UK course is needed. There is also a lack of consensus more widely in the field about the types of outcomes that caregiver interventions are aiming to influence (McKechnie et al., 2014) so further clarity on this issue is needed. This clarification may then aid in specifying the most appropriate outcomes for the DAC-UK course research to be considering.

Future research into the DAC-UK course may need to consider facilitator fidelity to the DAC course manual and slides, as seen in other studies in the field (Rapaport et al., 2021). This is important as fidelity increases the validity and reliability of the data collected as all participants are more likely to have received the same intervention and content, as intended in the original design of the course. Studies could incorporate a fidelity checklist to

capture whether the important components of the intervention are being met, giving each facilitator a score in terms of how they have met the necessary requirements.

4.6. Implications for Clinical Practice

The fundamental focus of this research was on providing a caregiver intervention, supported by empirical evidence, which can be feasibly introduced within a public health setting. This study has indicated that flexible and regular delivery would likely be the most effective means of dissemination given that caregivers often must balance their attendance alongside caregiving responsibilities as well as other commitments such as work. Monthly course dates, offered at different times of day including outside of regular working hours would be optimal in giving all caregivers the opportunity to attend.

Further to this, offering the course from the point of diagnosis of the PLWD would be anticipated to give the best opportunity for the course to be beneficial both to the caregiver but also to the PLWD. The course could be offered following diagnosis within memory clinics as part of the service pathway, which would also support caregivers in accessing further support through charities and third sector organisation for themselves and the PLWD, as early as possible, as these details are incorporated at the end of the DAC-UK course.

Although not possible in the current study, it is also worth considering delivery of the course to larger groups of caregivers, perhaps up to 15 or 20, where the course facilitators could split the participants into smaller groups for discussions. This would allow more caregivers to be reached and supported with fewer resources, a practical delivery advantage especially alongside the predicted cost-effectiveness of the intervention. This could also be worthwhile as a consideration given that caregivers often have to cancel attendance at short notice due to changes in schedules or caring cover as it would mean that the group sizes for clinical delivery would still be large enough for strong peer-to-peer interaction.

Consideration also needs to be given to the clinicians who would be best placed within a public health setting to deliver and facilitate the course, for example trainee clinical

psychologists or assistant psychologists. It could be worth considering focus groups or discussions with clinical teams working with dementia to get their thoughts and opinions on who would be best placed to deliver the course or how delivery could be achieved most effectively as they will have practice-based experience and knowledge.

5. Conclusion

As dementia diagnoses continue to increase, it is vital that suitable evidence-based caregiver interventions are offered throughout the UK. This study provides promising evidence that the DAC-UK course can provide a brief and proactive intervention for informal caregivers that is both feasible and acceptable. Further large-scale research is needed to strengthen this evidence and generalise the findings across the diverse populations of the UK via different delivery methods. Doing so will allow for the public health implementation of the DAC-UK course across dementia services in the UK, which will provide equity in high-quality care and support for the informal caregivers of people living with dementia.

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Part Three: Critical Appraisal

Introduction

This critical appraisal outlines my reflections on completing a research project within the Doctorate of Clinical Psychology. The appraisal will begin by considering the experiences that led me to pursue research in this area. I will then reflect on the research process considering the study design, recruitment, outcomes, and delivery. Finally, I will consider more widely the possible clinical impact and my recommendations regarding both research and clinical implementation.

Why this Research?

When it came to choosing a research area, I was immediately drawn to a project relating to dementia for several reasons.

Both of my grandmothers were diagnosed with dementia before they passed away and so I have seen first-hand the progressive nature of the disease and the impact it has not only on the individual but on those around them. I was struck by the apparent dearth of support following diagnosis and how the weight of supporting my grandmothers fell on my parents and their siblings. Although the practical elements of caregiving are perhaps discussed more, in terms of mobility aids, incontinence management and dementia adapted home appliances, I felt that my family were left alone with the emotional effects of dementia and managing the ever-changing relationship with their loved one.

My parents are both university-educated professionals with a strong grasp of current technology and how to search for information on the internet. They are also both fluent in English and able to make phone calls. These privileges meant that they were both able to access information and educate themselves independently about dementia. They were also able to contact support services and arrange help with finances, health and psychological wellbeing for my grandmothers. Further to this, self-employment and retirement meant that they did not have to worry about working patterns or their finances when having to travel at short notice to support my grandmothers or wait on the phone on hold for hours regarding disability allowances or council tax exemptions. I cannot help but wonder now, if they had not

had these privileges, how different their caregiving experience would have been, and the negative impact this could have had on everyone involved. Building on this, I wonder if sometimes dementia professionals can assume that members of the community have a better understanding of dementia than they do. Therefore, clinicians can forget that further support and education, which is accessible, may be vital for informal caregivers in adjusting to the diagnosis and knowing how to manage moving forwards.

In terms of professional experiences, I had previously worked in a community team for people with learning disabilities carrying out dementia assessments. This drew my attention to the lack of training for professionals in the caring sector on dementia with many not knowing what symptoms to look out for or what a diagnosis would mean. As a service, we started to deliver short training sessions about dementia for support workers, focussing on psychoeducation and available local resources. Only now, reflecting on this, am I aware that although this was a helpful step in supporting these professional caregivers, many of our clients were supported by family and friends and we did not offer any training to support these individuals.

Following on from this, I went on to work in an older adults' community mental health team, facilitating Cognitive Stimulation Therapy (CST) groups and caregiver training sessions. This was my first experience of training provided for informal caregivers. The training had been developed independently by the service as there was nothing offered within the National Health Service (NHS) more widely. It was immediately apparent to me how much the caregivers valued the training and also valued the space to connect with peers and be able to share their experiences. Considering the training from a more academic perspective, I was left curious as to how the training had been developed and researched prior to dissemination as there was no apparent evidence-base for its delivery.

In terms of the intervention itself, I was drawn to the simplicity of the Dementia Awareness for Caregivers (DAC) course. In my preliminary research of other interventions in the field, I noticed that many required attendance over multiple sessions and informal

caregivers only qualified for the interventions if they were already having difficulties with their mental health (Frias et al., 2020; Livingston et al., 2020). I was struck by the reactive nature of these interventions, waiting until the caregivers were struggling and their wellbeing having deteriorated before intervening. The complexity was also apparent with many interventions including a lot of different concepts delivered over many weeks. This repeated attendance is often difficult for informal caregivers to access given the other demands in their lives. In contrast with these interventions, the DAC course offered a proactive and preventative approach in one half-day session. For me, this felt not only likely to be more manageable for caregivers but also a much better approach, preventing burn out and emotional distress rather than waiting for it to occur. From a public health perspective, it would likely be much more cost and resource effective to prevent distress in caregivers rather than waiting to react once it arises. This would arguably be beneficial both in terms of the caregiver support needs but also the subsequent support needs of the person living with dementia who may then be institutionalised earlier if the caregiver feels that they cannot cope (Brodaty & Donkin, 2009).

Therefore, the development of a brief, proactive intervention for informal caregivers of people living with dementia felt both personally and professionally relevant. It also felt incredibly important, due to the increasing dementia diagnoses in the United Kingdom (UK) (Wittenberg et al., 2019) alongside the emotional impact of caregiving, to be able to carry out research that could go forward and have an impact within public health, rather than just in academia alone.

Study Design

This project was my first experience of post-graduate psychological research. I was drawn to the concept of a feasibility and acceptability study, not just because of the aforementioned relevant content, but also because of the value of the research. Feasibility studies shape future larger scale research trials and improve the quality of this future research (Eldridge et al., 2016). Thus, the study forms the first step in a process that can

lead to evidence-based interventions being implemented widely and successfully in clinical settings (Gadke et al., 2021). Despite this, I was surprised by the lack of clarity in the literature about what constitutes feasibility and acceptability of an intervention. Studies often do not provide specific thresholds for feasibility, in terms of recruitment or retention statistics (Chew-Graham et al., 2022; Rapaport et al., 2021). Researchers appear to make arbitrary judgments about whether they feel the evidence gathered in their study constitutes evidence of feasibility. I was surprised by this obscurity and how difficult it must therefore be to directly compare different interventions. When designing the study, we tried to base our own thresholds on other studies in the area and use reasonable judgment about acceptable levels of recruitment and retention to constitute feasibility. I wonder if clearer guidelines or agreed thresholds within feasibility research should be considered in research moving forwards.

The study design also meant that I had the opportunity to work collaboratively with another researcher in order to capture both quantitative and qualitative data. This felt valuable as it is important to capture the statistical and outcome driven data that can be generalised, but also the more individual level feedback (Richards et al., 2019). Our findings, in my opinion, would have been incomplete had only one form of data been collected and reported on, and our conclusions are much more valid and reputable with the mixed methods combination of data, especially at this early stage of intervention testing. I also think it is helpful to have more than one researcher in a study of this kind so that different perspectives can be captured within intervention design and adaptation, and to reduce possible participant bias in interviews, as the researcher that facilitated that course did not have to conduct the interview too.

Within the design of the DAC-UK course itself, it also felt incredibly worthwhile and important being able to involve stakeholders such as people living with dementia and informal caregivers. Evidence suggests that interventions designed with this input are more likely to have high levels of recruitment and retention as well as appropriate content and

outcomes measured for the target population (Domecq et al., 2014). It also felt pertinent given our overarching aim for the course to be delivered in public health settings for people in our target populations to be able to give their thoughts. I wonder now whether we should have looked to stakeholders outside of our personal connections in order to minimise any potential bias this may have caused. It is also worth considering the level of input stakeholders had the opportunity to provide. Arguably, there was active consultation in this project, but it would be worth developing this to active stakeholder involvement and partnership (Leslie et al., 2019) in the continued development of the DAC-UK course for different communities.

Reflection on this study design having completed the trial and research process, has drawn my attention to the non-standard approach we utilised in terms of randomisation. We completed randomisation prior to the participants completing their baseline measures where most other studies have baseline measures completed prior to randomisation (for example, Livingston et al., 2014). Considering this now, I can see that this was an oversight in terms of sound methodology as the participants already knew their condition which could have impacted how they completed the measures. This highlights to me the importance of not rushing the design process of a study and making sure to discuss all decisions and plans with the research team to prevent errors occurring. Given my inexperience with research, I can understand why this may not have occurred to me as an issue at the time, but I think now, slowing down the process and directly comparing my study plans with other protocols and trial methods would have been valuable and sensible.

Outcome Measures

Alongside the feasibility and acceptability measures within the study, we also felt it would be worthwhile to explore possible caregiver outcomes that may have been impacted by the DAC-UK course. Although there were no significant findings within the five measures that we chose, there were non-significant positive changes in four out of the five measures in favour of the DAC-UK course.

Through both the systematic review and my research for the empirical study, I repeatedly noticed the confusion in the field with regards to the outcomes being measured. There appears to be no consensus at present on which constructs are likely to be impacted, or which measures are most appropriate to capture these (Cheng et al., 2019). This, much like the lack of clarity regarding feasibility statistics, makes it challenging to quantitatively compare caregiver interventions. There is also the risk that this ambiguity can lead to poor prioritisation of outcomes meaning that caregivers must complete more questionnaires when taking part in research, which takes up more of their already pressured time (Drummond et al., 2019). Cheng et al. (2019) noted that there appears to be a dominance of certain constructs being measured, such as burden and quality of life, where others are neglected. There is no clear explanation for this bias within the literature. Similarly, Parker et al. (2008) reflected that there may be a divergence in opinion between researchers and caregivers in terms of which outcomes they would like to see influenced as a result of an intervention. Perhaps research has historically been more top-down in the selection of outcomes, as I have found little evidence to suggest intervention studies have considered caregiver hopes and perspectives in terms of the outcome measures selected. There is no doubt that a consensus needs to be reached within the field, not only for effective and ethical research practices but also to make sure that the interventions are targeting the areas that caregivers want to change.

I have also reflected since the completion of the study on the inclusion of the Approaches to Dementia (ADQ-19) questionnaire for a couple of reasons. Firstly, the language included within this questionnaire is no longer considered appropriate or in line with guidance on writing about dementia. Secondly, qualitative feedback from the caregivers in the interviews, which I could not capture within my quantitative paper, noted the inclusion of language in the measure which fits more for completion by professional caregivers. Language such as “residents” rather than family member or loved one living with dementia. I would consider in future seeking out a different measure that feels more appropriate and

fitting for this caregiver population, or that this measure will need re-validation for an informal caregiver population. I do note that I did research other options within the field when we started our project and could not find anything at present that is equivalent with suitable validity and reliability scores.

Recruitment

When we first started planning our study, we decided to apply for ethical approval via University College London (UCL) as we were aware that ethics applications through the NHS often take an extended period and come with increased complexity (Van Teijlingen et al., 2008). Due to the limited time frame that we had for the project, we felt it was more important to move forward with recruitment and data collection within the university ethical framework.

Throughout the recruitment process, I was torn between wanting to provide an intervention that I genuinely believe would help the caregivers and feeling uncomfortable asking caregivers to give up more of their precious time and energy to take part in the study. I was particularly aware of those in the control group that were not receiving a therapeutic research offer but rather a non-therapeutic request for their input (McKeown et al., 2010). Chandra et al. (2021) have also questioned the ethics of involving caregivers in this research if it does not then translate into policy change and effective clinical care, which was a concern of mine within this research area. I would consider, if I were to carry out a similar research study again, thinking about possible incentives or compensation that could be provided to the caregivers to demonstrate an awareness and appreciation of them having given up their time and energy. In addition, I think it could also be appropriate as part of a larger research trial to have the control condition as a waiting list group, so that all volunteers get to access the intervention.

Using Join Dementia Research (JDR) (Join Dementia Research, n.d.) was an easy and efficient means of recruitment, and it felt appropriate using an online platform given that the course itself was being delivered online. However, the resulting homogeneity of the

sample in terms of their reported ethnicity, as white, was at odds with the diversity of the UK population (Office for National Statistics, 2021). Given the DAC course focus on equity in support for caregivers, it felt uncomfortable to have only recruited white, computer literate caregivers. Especially as informal caregivers from minority ethnic backgrounds or migrant backgrounds have been documented to be less likely to engage in intervention research (Tezcan-Guntekin et al., 2022). Further attention needs to be given to how best to engage them in future studies investigating the DAC-UK course with perhaps more of a focus on building trust and relationships within communities prior to advertising (Emami & Mazaheri, 2007) and recruiting via community leaders (Tezcan-Guntekin et al, 2022). This will provide more ecologically valid results and hopefully demonstrate the adaptability of the DAC course template.

If I were to carry out this research again, or if I had had a longer time frame in which to complete this study, I would consider applying for NHS ethical approval and recruiting caregivers through NHS memory clinics. Not only would this provide an, arguably, more ecologically valid sample of caregivers but also it would provide an opportunity to trial the intervention in the setting that it would hopefully be delivered in moving forwards. Trialling the DAC-UK course in the NHS would also provide more realistic recruitment and retention statistics. It would also provide the opportunity to gather clinician feedback on how it fits within their service, and whether the content and delivery methods feel appropriate for the populations.

Facilitating the Intervention

Through the project, I delivered the DAC-UK course on three occasions. The delivery allowed me to develop my clinical skills in terms of communicating key messages at an appropriate level for the audience and managing participant emotions and disclosures within a group setting. This was an unexpected benefit of taking on a research project with the opportunity to deliver an intervention.

I was aware during delivery and on reflection that I was using my own knowledge about dementia from my previous roles alongside the course manual when giving explanations and answering participant questions. This has made me consider the need to evaluate fidelity in future studies of the DAC course. It is important to evaluate intervention fidelity during trials in order to check that all participants are receiving the same intervention and that key messages are not being missed by the facilitator, as seen in other studies in the field (Rapaport et al, 2021).

Caregiver feedback following the intervention included feelings of connection with the facilitator, and an increased investment in the content, when they disclosed their own personal experiences of caregiving or living alongside someone with dementia. As such, I have started to wonder whether future delivery of the DAC-UK course may benefit from also including an expert-by-experience such as a former caregiver to aid in the facilitation and participant engagement. I have yet to find any other interventions that have trialled this and would be curious to see whether it would increase the intervention impact for the caregivers, both qualitatively and quantitatively.

Clinical Impact

Throughout the process of completing both my systematic review and the empirical study, I have noticed how often research within the field does not translate into clinical implementation. There are plenty of studies and reviews on interventions for dementia caregivers (Gallagher-Thompson et al., 2012; Drummond et al., 2019), across many different countries. However, many of these interventions appear to be trialled once or only a handful of times and this often does not lead to any form of public health delivery. Approaching this project as a health professional working in clinical settings, rather than as an academic researcher, I was surprised and disappointed by this. This feels especially pertinent given the questions around ethical practice when research is not progressing into public health policy and implementation (Chandra et al., 2021). Therefore, it was important to me, that my

thesis project be part of a process with the main aim of public health implementation and clinical impact.

I think that the DAC course project more widely also signifies an important step in psychological research of considering worldwide equity of care. There is a long history of western psychological research and ideas dominating practice (Fernando & Campling, 2002) with research often feeling divided between countries and cultures. In contrast with this, the DAC course was designed to provide an international template that can be adapted for any population (Stoner et al., 2022) to fit with local caregiver needs, and has already been trialled in a number of different countries around the world.

The DAC-UK course provides an important potential intervention to fulfil the National Institute for Health and Care Excellence (NICE) guidelines recommendation of support for all informal caregivers of people living with dementia (NICE, 2018). With further larger research trials carried out, the DAC-UK course has the potential to be an accessible, proactive, and brief intervention that can be delivered without incurring high costs or resource needs, that can be tailored to meet different caregiver needs in different populations in the UK. It can then also fit within a larger DAC course project where informal caregivers all over the world could potentially receive the same intervention.

Recommendations

There are several recommendations that I would give following completion of this project with regards to the DAC-UK course.

As services return where possible and appropriate to face-to-face following the COVID-19 pandemic, it would be worthwhile to trial the DAC-UK course via in person delivery. Research has shown that participants can connect better with content when they are physically present rather than via a video platform (Friedman et al., 2009). I am also curious about whether participant engagement both with the facilitator and the course, but also with each other, would be greater without the barrier of screens. Alongside this, in

person delivery would also potentially allow for the DAC-UK course to reach a different population of caregivers, including those who do not have computer access or prefer to interact in physical settings. Comparison of the DAC-UK course delivered online versus in person in terms of feasibility, acceptability and caregiver preference would be interesting and relevant. Arguably, public health implementation would benefit from varied methods of delivery, to suit the population in question, but evidence supporting the different methods will first need to be found.

Our invited group sizes ranged from six to ten but were often smaller due to caregivers being unable to attend at short notice. Therefore, I would recommend organisers to invite more than the desired group size to each delivery of the DAC-UK course as it is unlikely, given the nature of their role, that all of the caregivers will be able to attend. We also found that reminder telephone calls and emails in the days leading up to the course were helpful in increasing attendance. In addition, regular delivery of the course on different days and different times, perhaps outside of working hours, would also provide more caregivers with the opportunity to attend around their other commitments. This was outside the scope of our small-scale study but would likely increase attendance and provide a more realistic means of delivery for clinical practice, whilst also demonstrating ecologically valid feasibility within a larger research trial. Relating to this, I think there is scope for the DAC-UK course to be delivered to larger groups of caregivers than we trialled within our study. It would be worth considering delivering the course to 15 to 20 caregivers at the time, offering small group exercises to facilitate discussions. This would mean that more caregivers can be reached more efficiently, limiting financial and staffing resources, which are important considerations when aiming for public health dissemination.

Further to this, as the DAC course project hopefully continues to grow, thought must also be given to who will facilitate the course and how they will be trained to do so. Perhaps a training video or an example of the course being delivered alongside the course slides and manual could provide suitable support for those learning to deliver it. Doing this would

hopefully make the training accessible to different facilitators, making sure it can have a positive and wide-reaching impact.

Conclusion

Overall, this project has been a positive experience, and I am glad that I was able to carry out research within a field that holds both personal and professional meaning to me. As it has been my first experience conducting research regarding a psychological intervention, I have learned a lot about the research process and the different areas that need to be considered within intervention development and delivery.

Both the systematic review and the empirical study have brought home to me just how great of a public health issue dementia is and how important it is that academic research translates into clinical implementation, with global equity in care also held at the forefront. I hope that the empirical study can be the start of continued research into the DAC-UK course that will translate into effective clinical practice. Attention must be given to diversifying the samples trialling the course, considering different delivery methods and group sizes whilst making sure facilitator fidelity to the course content remains high. Doing so, will hopefully allow for the DAC course to provide a brief, accessible, proactive, and adaptable intervention that can go on to improve the lives of caregivers across the UK as well as other countries around the world.

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Appendices

Appendix 1 - Search Terms

PsycINFO and MedLine (OVID)

1. exp Dementia/
2. (Alzheimer* or "Lewy body" or "Frontotemporal" or "Dement*" or "Vascular dementia" or "cognitive degeneration" or "cognitive impairment").mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
3. (Carer* or Caregive*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
4. (Famil* or informal or unpaid).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
5. (Support or Training or intervention or course or trial or group).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
6. (Awareness or Educa* or Psychoed*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
7. (afghanistan OR albania OR algeria OR american samoa OR angola OR "antigua and barbuda" OR antigua OR barbuda OR argentina OR armenia OR armenian OR aruba OR azerbaijan OR bahrain OR bangladesh OR barbados OR republic of belarus OR belarus OR byelarus OR belorussia OR byelorussian OR belize OR british honduras OR benin OR dahomey OR bhutan OR bolivia OR "bosnia and herzegovina" OR bosnia OR herzegovina OR botswana OR bechuanaland OR brazil OR brasil OR bulgaria OR burkina faso OR burkina fasso OR upper volta OR burundi OR urundi OR cabo verde OR cape verde OR cambodia OR kampuchea OR khmer republic OR cameroon OR cameron OR cameroun OR central african republic OR ubangi shari OR chad OR chile OR china OR colombia OR comoros OR comoro islands OR iles comores OR mayotte OR democratic republic of the congo OR democratic republic congo OR congo OR zaire OR costa rica OR "cote d'ivoire" OR "cote d'ivoire" OR cote divoire OR cote d ivoire OR ivory coast OR croatia OR cuba OR cyprus OR czech republic OR czechoslovakia OR djibouti OR french somaliland OR dominica OR dominican republic OR ecuador OR egypt OR united arab republic OR el salvador OR equatorial guinea OR spanish guinea OR eritrea OR estonia OR eswatini OR swaziland OR ethiopia OR fiji OR gabon OR gabonese republic OR gambia OR "georgia (republic)" OR georgian OR ghana OR gold coast OR gibraltar OR greece OR grenada OR guam OR guatemala OR guinea OR guinea bissau OR guyana OR british guiana OR haiti OR hispaniola OR honduras OR hungary OR india OR indonesia OR timor OR iran OR iraq OR isle of man OR jamaica OR jordan OR kazakhstan OR kazakh OR kenya OR

"democratic people's republic of korea" OR republic of korea OR north korea OR south korea OR korea OR kosovo OR kyrgyzstan OR kirghizia OR kirgizstan OR kyrgyz republic OR kirghiz OR laos OR lao pdr OR "lao people's democratic republic" OR latvia OR lebanon OR lebanese republic OR lesotho OR basutoland OR liberia OR libya OR libyan arab jamahiriya OR lithuania OR macau OR macao OR republic of north macedonia OR macedonia OR madagascar OR malagasy republic OR malawi OR nyasaland OR malaysia OR malay federation OR malaya federation OR maldives OR indian ocean islands OR indian ocean OR mali OR malta OR micronesia OR federated states of micronesia OR kiribati OR marshall islands OR nauru OR northern mariana islands OR palau OR tuvalu OR mauritania OR mauritius OR mexico OR moldova OR moldovian OR mongolia OR montenegro OR morocco OR ifni OR mozambique OR portuguese east africa OR myanmar OR burma OR namibia OR nepal OR netherlands antilles OR nicaragua OR niger OR nigeria OR oman OR muscat OR pakistan OR panama OR papua new guinea OR new guinea OR paraguay OR peru OR philippines OR philipines OR phillippines OR philippines OR poland OR "polish people's republic" OR portugal OR portuguese republic OR puerto rico OR romania OR russia OR russian federation OR ussr OR soviet union OR union of soviet socialist republics OR rwanada OR ruanda OR samoa OR pacific islands OR polynesia OR samoan islands OR navigator island OR navigator islands OR "sao tome and principe" OR saudi arabia OR senegal OR serbia OR seychelles OR sierra leone OR slovakia OR slovak republic OR slovenia OR melanesia OR solomon island OR solomon islands OR norfolk island OR norfolk islands OR somalia OR south africa OR south sudan OR sri lanka OR ceylon OR "saint kitts and nevis" OR "st. kitts and nevis" OR saint lucia OR "st. lucia" OR "saint vincent and the grenadines" OR saint vincent OR "st. vincent" OR grenadines OR sudan OR suriname OR surinam OR dutch guiana OR netherlands guiana OR syria OR syrian arab republic OR tajikistan OR tadjikistan OR tadhikistan OR tadhik OR tanzania OR tanganyika OR thailand OR siam OR timor leste OR east timor OR togo OR togolese republic OR tonga OR "trinidad and tobago" OR trinidad OR tobago OR tunisia OR turkey OR turkmenistan OR turkmen OR uganda OR ukraine OR uruguay OR uzbekistan OR uzbek OR vanuatu OR new hebrides OR venezuela OR vietnam OR viet nam OR middle east OR west bank OR gaza OR palestine OR yemen OR yugoslavia OR zambia OR zimbabwe OR northern rhodesia OR global south OR africa south of the sahara OR sub-saharan africa OR subsaharan africa OR africa, central OR central africa OR africa, northern OR north africa OR northern africa OR magreb OR maghrib OR sahara OR africa, southern OR southern africa OR africa, eastern OR east africa OR eastern africa OR africa, western OR west africa OR western africa OR west indies OR indian ocean islands OR caribbean OR central america OR latin america OR "south and central america" OR south america OR asia, central OR central asia OR asia, northern OR north asia OR northern asia OR asia, southeastern OR southeastern asia OR south eastern asia OR southeast asia OR south east asia OR asia, western OR western asia OR europe, eastern OR east europe OR eastern europe OR developing country OR developing countries OR developing nation? OR developing population? OR developing world OR less developed countr* OR less developed nation? OR less developed population? OR less developed world OR lesser developed countr* OR lesser developed nation? OR lesser developed population? OR lesser developed world OR under developed countr* OR under developed nation? OR under developed population? OR under developed world OR underdeveloped countr* OR underdeveloped nation? OR underdeveloped population? OR underdeveloped world OR middle income countr* OR middle income nation? OR middle income population? OR low income countr* OR low income nation? OR low income population? OR lower income countr* OR lower income nation? OR lower income population? OR underserved countr* OR underserved nation? OR underserved population? OR underserved world OR under served countr* OR under served nation? OR under served population? OR under served world OR deprived

countr* OR deprived nation? OR deprived population? OR deprived world OR poor countr* OR poor nation? OR poor population? OR poor world OR poorer countr* OR poorer nation? OR poorer population? OR poorer world OR developing econom* OR less developed econom* OR lesser developed econom* OR under developed econom* OR underdeveloped econom* OR middle income econom* OR low income econom* OR lower income econom* OR low gdp OR low gnp OR low gross domestic OR low gross national OR lower gdp OR lower gnp OR lower gross domestic OR lower gross national OR Imic OR Imics OR third world OR lami countr* OR transitional countr* OR emerging economies OR emerging nation?).ti,ab,sh,kf.

8. 1 and 2 and 3 and 4 and 5 and 6 and 7

Web of Sciences

Dementia OR Alzheimer* OR "Lewy bod*" OR "Frontotemporal" OR "Dement*" OR "Vascular dementia" OR "cognitive* degeneration" OR "cognitive impairment" (Topic) and Carer* OR Caregive* (Topic) and Support or Training or intervention or course or trial or education or awareness (Topic) and afghanistan or albania or algeria or american samoa or angola or "antigua and barbuda" or antigua or barbuda or argentina or armenia or armenian or aruba or azerbaijan or bahrain or bangladesh or barbados or republic of belarus or belarus or byelarus or belorussia or byelorussian or belize or british honduras or benin or dahomey or bhutan or bolivia or "bosnia and herzegovina" or bosnia or herzegovina or botswana or bechuanaland or brazil or brasil or bulgaria or burkina faso or burkina fasso or upper volta or burundi or urundi or cabo verde or cape verde or cambodia or kampuchea or khmer republic or cameroon or cameron or cameroun or central african republic or ubangi shari or chad or chile or china or colombia or comoros or comoro islands or iles comores or mayotte or democratic republic of the congo or democratic republic congo or congo or zaire or costa rica or "cote d'ivoire" or "cote d'ivoire" or cote divoire or cote d ivoire or ivory coast or croatia or cuba or cyprus or czech republic or czechoslovakia or djibouti or french somaliland or dominica or dominican republic or ecuador or egypt or united arab republic or el salvador or equatorial guinea or spanish guinea or eritrea or estonia or eswatini or swaziland or ethiopia or fiji or gabon or gabonese republic or gambia or "georgia (republic)" or georgian or ghana or gold coast or gibraltar or greece or grenada or guam or guatemala or guinea or guinea bissau or guyana or british guiana or haiti or hispaniola or honduras or hungary or india or indonesia or timor or iran or iraq or isle of man or jamaica or jordan or kazakhstan or kazakh or kenya or "democratic people's republic of korea" or republic of korea or north korea or south korea or korea or kosovo or kyrgyzstan or kirghizia or kirgizstan or kyrgyz republic or kirghiz or laos or lao pdr or "lao people's democratic republic" or latvia or lebanon or lebanese republic or lesotho or basutoland or liberia or libya or libyan arab jamahiriya or lithuania or macau or macao or republic of north macedonia or macedonia or madagascar or malagasy republic or malawi or niasaland or malaysia or malay federation or malaya federation or maldives or indian ocean islands or indian ocean or mali or malta or micronesia or federated states of micronesia or kiribati or marshall islands or nauru or northern mariana islands or palau or tuvalu or mauritania or mauritius or mexico or moldova or moldovian or mongolia or montenegro or morocco or ifni or mozambique or portuguese east africa or myanmar or burma or namibia or nepal or netherlands antilles or nicaragua or niger or nigeria or oman or muscat or pakistan or panama or papua new guinea or new guinea or paraguay or peru or philippines or philippines or phillipines or philippines or poland or "polish people's republic" or portugal or portuguese republic or puerto rico or romania or russia or russian federation or ussr or soviet union or union of soviet socialist republics or rwanda or ruanda or samoa or pacific islands or polynesia or samoan islands or navigator island or navigator islands or "sao tome and principe" or saudi arabia or senegal or serbia or

seychelles or sierra leone or slovakia or slovak republic or slovenia or melanesia or solomon island or solomon islands or norfolk island or norfolk islands or somalia or south africa or south sudan or sri lanka or ceylon or "saint kitts and nevis" or "st. kitts and nevis" or saint lucia or "st. lucia" or "saint vincent and the grenadines" or saint vincent or "st. vincent" or grenadines or sudan or suriname or surinam or dutch guiana or netherlands guiana or syria or syrian arab republic or tajikistan or tadjikistan or tadjhikistan or tadjhik or tanzania or tanganyika or thailand or siam or timor leste or east timor or togo or togolese republic or tonga or "trinidad and tobago" or trinidad or tobago or tunisia or turkey or turkmenistan or turkmen or uganda or ukraine or uruguay or uzbekistan or uzbek or vanuatu or new hebrides or venezuela or vietnam or viet nam or middle east or west bank or gaza or palestine or yemen or yugoslavia or zambia or zimbabwe or northern rhodesia or global south or africa south of the sahara or sub-saharan africa or subsaharan africa or africa, central or central africa or africa, northern or north africa or northern africa or magreb or maghrib or sahara or africa, southern or southern africa or africa, eastern or east africa or eastern africa or africa, western or west africa or western africa or west indies or indian ocean islands or caribbean or central america or latin america or "south and central america" or south america or asia, central or central asia or asia, northern or north asia or northern asia or asia, southeastern or southeastern asia or south eastern asia or southeast asia or south east asia or asia, western or western asia or europe, eastern or east europe or eastern europe or developing country or developing countries or developing nation? or developing population? or developing world or less developed countr* or less developed nation? or less developed population? or less developed world or lesser developed countr* or lesser developed nation? or lesser developed population? or lesser developed world or under developed countr* or under developed nation? or under developed population? or under developed world or underdeveloped countr* or underdeveloped nation? or underdeveloped population? or underdeveloped world or middle income countr* or middle income nation? or middle income population? or low income countr* or low income nation? or low income population? or lower income countr* or lower income nation? or lower income population? or underserved countr* or underserved nation? or underserved population? or underserved world or under served countr* or under served nation? or under served population? or under served world or deprived countr* or deprived nation? or deprived population? or deprived world or poor countr* or poor nation? or poor population? or poor world or poorer countr* or poorer nation? or poorer population? or poorer world or developing econom* or less developed econom* or lesser developed econom* or under developed econom* or underdeveloped econom* or middle income econom* or low income econom* or lower income econom* or low gdp or low gnp or low gross domestic or low gross national or lower gdp or lower gnp or lower gross domestic or lower gross national or lmic or lmic or third world or lami countr* or transitional countr* or emerging economies or emerging nation (Topic)

Scopus Search

TITLE-ABS-KEY (afghanistan OR albania OR algeria OR "American samoa" OR angola OR "antigua and barbuda" OR antigua OR barbuda OR argentina OR armenia OR armenian OR arub a OR azer aijan OR bahrain OR bangladesh OR barbados OR "republic of belarus" OR belarus OR byelarus OR belorussia OR byelorussian OR belize OR "brit ish honduras" OR benin OR dahomey OR bhutan OR bolivia OR "bosnia and herzegovina" OR bosnia OR herzegovina OR botswana OR bechuanaland OR brazil OR brasil OR bulgaria OR "burkina faso" OR "burkina fasso" OR "upper volta" OR burundi OR urundi OR "cabo verde" OR "cape verde" OR cambodia OR kampuchea OR "khmer republic" OR cameroon OR cameron OR cameroun OR "central african

republic" OR "ubangi shari" OR chad OR chile OR china OR colombia OR comoros OR "comoro islands" OR "iles comores" OR mayotte OR "democratic republic of the congo" OR "democratic republic congo" OR congo OR zaire OR "costa rica" OR "cote d'ivoire" OR "cote d'ivoire" OR "cote divoire" OR "cote d ivoire" OR "ivory coast" OR croatia OR cuba OR cyprus OR "czech republic" OR czechoslovakia OR djibouti OR "french somaliland" OR dominica OR "dominican republic" OR ecuador OR egypt OR "united arab republic" OR "el salvador" OR "equatorial guinea" OR "Spanish guinea" OR eritrea OR estonia OR eswatini OR swaziland OR ethiopia OR fiji OR gabon OR "gabonese republic" OR gambia OR "georgia (republic)" OR georgia OR georgian OR ghana OR "gold coast" OR gibraltar OR greece OR grenada OR guam OR guatemala OR guinea OR "guinea bissau" OR guyana OR "british guiana" OR haiti OR hispaniola OR honduras OR hungary OR india OR indonesia OR timor OR iran OR iraq OR "isle of man" OR jamaica OR jordan OR kazakhstan OR kazakh OR kenya OR "democratic people's republic of korea" OR "republic of korea" OR north AND korea OR south AND korea OR korea OR kosovo OR kyrgyzstan OR kirghizia OR kirgizstan OR "kyrgyz republic" OR kirghiz OR laos OR "lao pdr" OR "lao people's democratic republic" OR latvia OR lebanon OR "lebanese republic" OR lesotho OR basutoland OR liberia OR libya OR "libyan arab jamahiriya" OR lithuania OR macau OR macao OR "republic of north macedonia" OR macedonia OR madagascar OR "malagasy republic" OR malawi OR nyasaland OR malaysia OR "malay federation" OR "malaya federation" OR maldives OR "indian ocean islands" OR "indian ocean" OR mali OR malta OR micronesia OR "federated states of micronesia" OR kiribati OR "marshall islands" OR nauru OR "northern mariana islands" OR palau OR tuvalu OR mauritania OR mauritius OR mexico OR moldova OR moldovian OR mongolia OR montenegro OR morocco OR ifni OR mozambique OR "portuguese east africa" OR myanmar OR burma OR namibia OR nepal OR "netherlands antilles" OR nicaragua OR niger OR nigeria OR oman OR muscat OR pakistan OR panama OR "papua new guinea" OR paraguay OR peru OR philippines OR philipines OR phillipines OR philippines OR poland OR "polish people's republic" OR portugal OR "portuguese republic" OR "puerto rico" OR romania OR russia OR "russian federation" OR ussr OR "soviet union" OR "union of soviet socialist republics" OR rwanda OR ruanda OR samoa OR "pacific islands" OR polynesia OR "samoan islands" OR "navigator island" OR "navigator islands" OR "sao tome and principe" OR "saudi arabia" OR senegal OR serbia OR seychelles OR "sierra leone" OR slovakia OR "slovak republic" OR slovenia OR melanesia OR "solomon island" OR "solomon islands" OR "norfolk island" OR "norfolk islands" OR somalia OR "south africa" OR "south sudan" OR "sri lanka" OR ceylon OR "saint kitts and nevis" OR "st. kitts and nevis" OR "saint lucia" OR "st. lucia" OR "saint vincent and the grenadines" OR "saint vincent" OR "st. vincent" OR grenadines OR sudan OR suriname OR surinam OR "dutch guiana" OR "netherlands guiana" OR syria OR "syrian arab republic" OR tajikistan OR tadjikistan OR tadjhikistan OR tadjhik OR tanzania OR tanyanyika OR thailand OR siam OR "timor leste" OR "east

timor" OR togo OR "togolese republic" OR tonga OR "trinidad and tobago" OR trinidad OR tobago OR tunisia OR turkey OR turkmenistan OR turkmen OR uganda OR ukraine OR uruguay OR uzbekistan OR uzbek OR vanuatu OR "new hebrides" OR venezuela OR vietnam OR "viet nam" OR "middle east" OR "west bank" OR gaza OR palestine OR yemen OR yugoslavia OR zambia OR zimbabwe OR "northern rhodesia" OR "global south" OR "africa south of the sahara" OR "sub saharan africa" OR "subsaharan africa" OR "africa, central" OR "central africa" OR "africa, northern" OR "north africa" OR "northern africa" OR magreb OR maghrib OR sahara OR "africa, southern" OR "southern africa" OR "africa, eastern" OR "east africa" OR "eastern africa" OR "africa, western" OR "west africa" OR "western africa" OR "west indies" OR "indian ocean islands" OR caribbean OR "central america" OR "latin america" OR "south and central america" OR "south america" OR "asia, central" OR "central asia" OR "asia, northern" OR "north asia" OR "northern asia" OR "asia, southeastern" OR "southeastern asia" OR "south eastern asia" OR "southeast asia" OR "south east asia" OR "asia, western" OR "western asia" OR "europe, eastern" OR "east europe" OR "eastern europe" OR "developing country" OR "developing countries" OR "developing nation" OR "developing nations" OR "developing population" OR "developing populations" OR "developing world" OR "less developed country" OR "less developed countries" OR "less developed nation" OR "less developed nations" OR "less developed population" OR "less developed populations" OR "less developed world" OR "lesser developed country" OR "lesser developed countries" OR "lesser developed nation" OR "lesser developed nations" OR "lesser developed population" OR "lesser developed populations" OR "lesser developed world" OR "under developed country" OR "under developed countries" OR "under developed nation" OR "under developed nations" OR "under developed population" OR "under developed populations" OR "under developed world" OR "underdeveloped country" OR "underdeveloped countries" OR "underdeveloped nation" OR "underdeveloped nations" OR "underdeveloped population" OR "underdeveloped populations" OR "underdeveloped world" OR "middle income country" OR "middle income countries" OR "middle income nation" OR "middle income nations" OR "middle income population" OR "middle income populations" OR "low income country" OR "low income countries" OR "low income nation" OR "low income nations" OR "low income population" OR "low income populations" OR "lower income country" OR "lower income countries" OR "lower income nation" OR "lower income nations" OR "lower income population" OR "lower income populations" OR "underserved country" OR "underserved countries" OR "underserved nation" OR "underserved nations" OR "underserved population" OR "underserved populations" OR "underserved world" OR "under served country" OR "under served countries" OR "under served nation" OR "under served nations" OR "under served population" OR "under served populations" OR "under served world" OR "deprived country" OR "deprived countries" OR "deprived nation" OR "deprived nations" OR "deprived population" OR "deprived populations" OR "deprived world" OR "poor country" OR "poor countries" OR "poor nation" OR "poor nations" OR "poor population" OR "poor populations" OR "poor world" OR "poorer country" OR "poorer countries" OR "poorer nation" OR "poorer nations" OR "poorer population" OR "poorer populations" OR "poorer world" OR "developing economy" OR "developing economies" OR "less developed economy" OR "less developed economies" OR "lesser developed economy" OR "lesser developed economies" OR "under developed economy" OR "under developed economies" OR "underdeveloped economy" OR "underdeveloped

economies" OR "middle income economy" OR "middle income economies" OR "low income economy" OR "low income economies" OR "lower income economy" OR "lower income economies" OR "low gdp" OR "low gnp" OR "low gross domestic" OR "low gross national" OR "lower gdp" OR "lower gnp" OR "lower gross domestic" OR "lower gross national" OR Imic OR Imics OR "third world" OR "lami country" OR "lami countries" OR "transitional country" OR "transitional countries" OR "emerging economies" OR "emerging nation" OR "emerging nations") AND ((TITLE-ABS-KEY (dementia OR alzheimer* OR "Lewy bod*" OR "Frontotemporal" OR "Dement*" OR "Vascular dementia" OR "cognitive* degeneration" OR "cognitive impairment") AND TITLE-ABS-KEY (carer* OR caregive*) AND TITLE-ABS-KEY (informal OR unpaid OR famil*) AND TITLE-ABS-KEY (support OR training OR intervention OR course OR trial OR education OR awareness)))

Google Scholar

dementia education carers LMICs

dementia education training carers caregivers LMICs

dementia Alzheimer's intervention carers caregivers LMICs

Appendix 2 – Overview of contributions to joint thesis research project

Izzy Evans (IE) and Ria Patel (RP) were individually and jointly responsible for different components of this project, as summarised below. Both theses were written up independently. Other researchers were also involved during the project and their contributions are also summarised below.

Task	Contributor
Conceptual Introduction	RP
Systematic Literature Review	IE
Systematic Review quality appraisal	IE (RP supported in inter-rater reliability checks)
Design of empirical study	RP and IE, under supervision of Professor Aimee Spector and Dr Charlotte Stoner
Ethics Application	RP and IE
Registration of Study with Clinicaltrials.gov	IE
Development of local version of DAC Course	RP and IE. Reviewed by Dr Charlotte Stoner
Stakeholder Feedback	RP and IE
Study Poster	RP (reviewed by IE)
Signing up with Join Dementia Research	IE (discussed with RP)
Recruitment	RP and IE
Development of Outcome Questionnaires	IE (reviewed by Professor Aimee Spector and Dr Charlotte Stoner; discussed with RP)
Development of Interview Questions	RP (reviewed by Professor Aimee Spector and Dr Charlotte Stoner; discussed with IE)
Delivery of DAC course	IE delivered 3 rounds of the DAC course RP delivered 1 rounds of the DAC course
Collection of post-DAC outcome measures	IE
Post-DAC interviews	IE conducted 6 interviews RP conducted 9 interviews
Data Entry and Storage	RP and IE
Transcription of Interviews	RP
Data Analysis	RP completed analysis on qualitative feedback interviews (IE supported in inter-rater reliability checks) IE completed analysis on quantitative outcome measures

Appendix 3 – Ethical approval letter from UCL Research Ethics Committee

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH



7th June 2022

Professor Aimee Spector
Faculty of Brain Sciences
UCL

Cc: Ria Patel and Izzy Evans

Dear Professor Spector

Notification of Ethics Approval

Project ID: 22375.001

Title: Investigating the feasibility, acceptability and impact of an online UK “Dementia Awareness Course” for unpaid caregivers.

Further to your satisfactory responses to the reviewer’s comments, I am pleased to confirm that your study has been ethically approved by the UCL Research Ethics Committee until **7th June 2023**.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair’s approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an ‘Amendment Approval Request Form’ - <https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval>

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
<http://ethics.grad.ucl.ac.uk/>

occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol.

The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

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Appendix 4 – Participant consent form

CONSENT FORM

UCL Research Ethics Committee Approval ID Number: 22375/001

Title of Study: Investigating the feasibility, acceptability and impact of an online UK “Dementia Awareness Course” for unpaid caregivers.

Department: Clinical, Educational and Health Psychology, Faculty of Brain Sciences, Division of Psychology and Language Sciences, UCL

Name and Contact Details of the Researcher(s): Ria Patel (r.patel.20@ucl.ac.uk) & Izzy Evans (izzy.evans.20@ucl.ac.uk)

Name and Contact Details of the Principal Researcher: Professor Aimee Spector (a.spector@ucl.ac.uk)

Name and Contact Details of the UCL Data Protection Officer:

This study has been approved by the UCL Research Ethics Committee: Project ID number:

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

Participant Identification Number for this project:

1	I confirm that I have read and understood the Participant Information Sheet dated 02.2022 for the above project. I have had the opportunity to consider this information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, up until data analysis. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	<input type="checkbox"/>
3	I consent to participate in the study. I understand that my personal information (age, ethnicity, gender, telephone number, email address) will	<input type="checkbox"/>

	be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.	
4	<p>Use of the information for this project only</p> <p>I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified (unless you state otherwise, because of the research design or except as required by law).</p> <p>I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.</p>	<input type="checkbox"/>
5	I understand that my information may be subject to review by responsible individuals from the University (to include sponsors and funders) for monitoring and audit purposes.	<input type="checkbox"/>
6	I understand the direct/indirect benefits of participating.	<input type="checkbox"/>
7	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	<input type="checkbox"/>
8	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	<input type="checkbox"/>
9	If I am asked to engage in an interview as part of the study, I consent to my interview being audio recorded and understand that the recordings will be stored anonymously, using password-protected software and destroyed immediately following transcription.	<input type="checkbox"/>
10	I consent to information and quotations from the transcript of the interview being published in the final report (confidentiality and anonymity will be maintained and it will not be possible to identify you from the publication).	<input type="checkbox"/>
11	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	<input type="checkbox"/>
12	I am aware of who I should contact if I wish to lodge a complaint.	<input type="checkbox"/>
13	I voluntarily agree to take part in the above project.	<input type="checkbox"/>

Name of Participant

Date

Signature

Appendix 5 – Study poster advertisement



A STUDY FOR CAREGIVERS OF PEOPLE LIVING WITH DEMENTIA

TITLE: Investigating the feasibility, acceptability and impact of an online UK "Dementia Awareness Course" for unpaid caregivers.

Who? Are you an unpaid caregiver to someone living with dementia? If so, you are being invited to take part in a study to understand your experience of providing care.

Why? Your participation in the study will help us better understand your experiences and investigate the acceptability, feasibility, and possible outcomes of a 'Dementia Awareness Course (DAC)' for a UK audience.

What? You will be asked to fill out an online questionnaire at two different time points, about a month apart. You may also be invited to attend a half-day online Dementia Awareness Course followed by an in-depth 30-minute interview about your experiences with one researcher. Any responses or comments from this study that we quote in our final report will be anonymized.

Interested?

Contact:
Ria Patel (r.patel.20@ucl.ac.uk) or
Izzy Evans (izzy.evans.20@ucl.ac.uk)

Following an expression of interest, you will be sent an information sheet about the study for further consideration.

UCL Ethics Approval number: 22375/001

Appendix 6 – Participant information sheet

RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY

Participant Information Sheet

UCL Research Ethics Committee Approval ID Number: 22375/001

Title of Study: Investigating the feasibility, acceptability, and impact of an online UK “Dementia Awareness Course” for unpaid caregivers.

Department: Clinical, Educational and Health Psychology, Faculty of Brain Sciences, Division of Psychology and Language Sciences, UCL

You are being invited to take part in a study to trial a new online Dementia Awareness Course, that is designed to support unpaid caregivers providing care to a person living with Dementia in the community. The study also aims to understand more about the experiences of these caregivers and how this may relate to the course content. This project can help us understand the benefits, barriers, acceptability, and feasibility of the course and whether it could be helpful if it could be delivered to caregivers more widely in the UK.

This doctoral research study is being conducted through the University College London by Ria Patel and Isabelle Evans, supervised by Professor Aimee Spector and Dr Charlotte Stoner. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide if you would like to take part in this study. Thank you for taking the time to read this information sheet.

What is the purpose of this study?

The purpose of this study is to investigate the possible impact of our ‘Dementia Awareness Course’ for caregivers alongside understanding your caregiving experiences and collecting your feedback. Your participation can help us to assess whether the course is a feasible and helpful intervention and shape our future delivery and planning.

What is the Dementia Awareness Course?

The course will be led by a Trainee Clinical Psychologist and will take place on one day over 3 – 4 hours with regular breaks. The course will be online using Zoom. Our aim is to deliver it to small groups of caregivers (5-10 individuals) with lots of space for interaction, sharing and discussions. The modules covered have been designed for a UK audience and cover these areas:

- What is Dementia?
- Positive Engagement
- Caring for someone with Dementia.

Why have I been invited to take part in this study?

You have been invited to take part because you are an adult (18 years and above) largely involved in caring for a person living with dementia. You may have received information through the Join

Dementia Research network, through a social media advertisement or through a local charity or group that you are connected to.

Do I have to take part?

Participation in this study is voluntary. It is up to you to decide if you would like to take part in this study. If you do decide to take part, you will be given this information sheet for your reference and asked to sign a consent form. You may withdraw from the study at any time up until data analysis. You do not have to give a reason for withdrawal. If you decide to withdraw you will be asked what you wish to happen to the data, you have provided up to that point. Taking part will not in any way affect any support you may or may not receive around your role as a caregiver.

What will happen to me if I take part?

The study is made up of two different groups. The first group will be invited to complete two sets of online questionnaires, a month apart, that should take no more than 30 minutes to complete at each time point.

The second group will be invited to complete these questionnaires and also, to attend the Dementia Awareness Course. One month following this, these participants will also be invited to attend a brief interview with one researcher to give their thoughts and feedback on the course.

You will be randomly allocated to one of these two groups, so there is a 50% chance that you will take part in the Dementia Awareness Course and interviews. This is so we can compare responses from people who took the course and people who did not.

All interviews will be recorded, and this recording will be stored securely. The recordings will only include audio and will not include video footage. In our reports, you will not be identified by name, but by a code number. We will analyse the voice recordings and questionnaire responses on secure computers that will only be accessed by members of the research team. Any responses or comments from this study that we quote in our final report will be anonymized

What are the possible disadvantages and risks of taking part?

This study may take up some of your time and we will ask you to reflect on your personal experiences. There are no other disadvantages or risks in participating in this study.

Will my taking part in this project be kept confidential?

All the information that we collect about you during this study will be kept strictly confidential and any external agencies used for transcription and analysis will be compliant with data protection legislation (General Data Protection Regulation, 2018). You will not be able to be identified in any ensuing reports or publications.

Please note that there are limits to confidentiality and the research team has a legal duty to report to the relevant authorities, possible harm or danger to the participant or others, professional misconduct or disclosures of criminal activity.

What will happen to the results of the research project?

The results of this study will be presented and released within two Doctoral theses in September 2023. The findings may also be published in a scientific journal. Copies of the results will be available to you on request after the data collection is finished and the analyses have been performed. Your name will not be linked to the publication in any way.

Local Data Protection Privacy Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Contact for further information

For further information please contact:

Principal Researcher: Professor Aimee Spector – Professor of Old Age Clinical Psychology – a.spector@ucl.ac.uk

Researchers: Ria Patel and Isabelle Evans – Trainee Clinical Psychologists – r.patel.20@ucl.ac.uk / izzy.evans.20@ucl.ac.uk

If you have complaints regarding the conduct of the study please contact: Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research study.

Appendix 7 – Email sent to participants.

Dear X

We hope you are well.

Our names are Ria Patel and Izzy Evans, and we are Trainee Clinical Psychologists at UCL.

We are currently recruiting participants for our doctoral research project. We have identified you through Join Dementia Research as a potential volunteer. Our study - Investigating the feasibility, acceptability and impact of an online UK “Dementia Awareness Course” for unpaid caregivers - is designed to support **unpaid caregivers currently providing care** to a person living with Dementia in the community. The study also aims to understand more about the experiences of these caregivers and how this may relate to the course content.

Please follow the below link to see an information sheet and consent form with more details about what is involved in taking part-

https://uclpsych.eu.qualtrics.com/jfe/form/SV_0rHluvZvbTTL2q

If you would like to continue and take part in the study, please complete the consent form in the link and we will add your name to the participant list. We will then be in contact when the study begins in August. The study is made up of two different groups (one questionnaire group and one interactive small course group) - **Please note: there is a 50% chance that you will be allocated to the course group so you may need to be available on DATE and DATE for the study.**

Thank you for taking the time to consider our study.

Yours Sincerely

Ria Patel and Izzy Evans

Researchers

Appendix 8 – Participant demographics questionnaire

Gender: _____

Current age: _____

Ethnicity: _____

Marital status:

- Single
- Married
- Widowed
- Divorced
- Living with partner
- Other (please specify):

Education level:

- None
- Minimal
- Completed Primary
- Completed Secondary (metric)
- Completed Tertiary (college)
- Other (please specify)

Relation to the person with dementia

- Spouse
- Son / Daughter
- Son-in-law / Daughter-in-law
- Sibling
- Other relative
- Friend
- Neighbour
- Other (please specify)

Do you normally live with the person with dementia?

- No
- Yes

Do you provide help and support to anyone else than the person with dementia?

- No
- Yes, child(ren)
- Yes, other adult(s)

How many other caregivers are involved in the care?

- 0
- 1
- 2
- 3
- 4 or more

Among all caregivers what is your level of contribution?

- 1 – 20%
- 21 – 40%
- 41 – 60%
- 61 – 80%
- 81 – 100%

Appendix 9 – End of participation information sheet

RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY

Participant Information Sheet – Post Study Completion

UCL Research Ethics Committee Approval ID Number: 22375/001

Title of Study: Investigating the feasibility, acceptability and impact of an online UK “Dementia Awareness Course” for unpaid caregivers.

Department: Clinical, Educational and Health Psychology, Faculty of Brain Sciences, Division of Psychology and Language Sciences, UCL

Thank you for taking part in our study.

Please find below information summarising the purpose of the research and providing contact details.

This doctoral research study is being conducted through the University College London by Ria Patel and Isabelle Evans, supervised by Professor Aimee Spector.

The purpose of this study was to understand your experiences as a caregiver and explore the impact of the ‘Dementia Awareness Course (DAC)’ on these experiences. As such, there were two different groups within the study. The first group were asked to complete the questionnaire about their experiences about a month apart. The second group were also asked to complete the questionnaire at the two time points but also took part in a half day ‘Dementia Awareness Course (DAC)’ and a follow-up interview. This allows us to investigate the acceptability, feasibility and possible outcomes of the ‘Dementia Awareness Course (DAC)’ for a UK audience.

Our aim is to use this study to better understand caregiver experiences and consider how our intervention may be able to be implemented in the future to support a large number of caregivers across the UK.

If your participation in our study has made you want to seek further support or talk about your experiences further, please find a list of possible contacts which we would encourage you to use as you feel necessary:

NHS - <https://www.nhs.uk/conditions/dementia/carers/>

Alzheimer’s Society – Dementia Connect support line - 0333 150 3456

Dementia UK – 0800 888 6678, helpline@dementiauk.org

Age UK Advice Line – 0800 678 1602

Independent Age Helpline – 0800 319 6789

Carers Direct helpline – 0300 123 1053

Carers UK Helpline – 0800 808 7777

Samaritans – 116 123

Will my taking part in this project be kept confidential?

All the information that we have collected about you during this study will be kept strictly confidential and any external agencies used for transcription and analysis will be GDPR compliant. You will not be able to be identified in any ensuing reports or publications.

Confidentiality may be limited and conditional and the researchers have a duty of care to report to the relevant authorities, possible harm/danger to the participant or others.

What will happen to the results of the research project?

The results of this study will be presented and released within two Doctoral theses in September 2023. The findings may also be published in a scientific journal. Copies of the results will be available to you on request after the data collection is finished and the analyses have been performed. Your name will not be linked to the publication in any way.

Local Data Protection Privacy Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Contact for further information

For further information please contact:

Principal Researcher: Professor Aimee Spector – Professor of Old Age Clinical Psychology – a.spector@ucl.ac.uk

Researchers: Ria Patel and Isabelle Evans – Trainee Clinical Psychologists – r.patel.20@ucl.ac.uk / izzy.evans.20@ucl.ac.uk

If you have complaints regarding the conduct of the study, please contact: Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

Thank you again for taking part in this research study.

Appendix 10 – Short Sense of Competence Questionnaire

(Vernooij-Dassen et al., 1999)

		Agree very strongly	Agree	Neutral	Disagree	Disagree very strongly
1	I feel that my ... behaves the way s/he does to have her/his own way.					
2	I feel that my ... behaves the way s/he does to annoy me.					
3	I feel that my ... tries to manipulate me.					
4	I feel strained in my interaction with my ...					
5	I wish that my ... and I had a better relationship.					
6	I feel stressed between trying to give to my ... as well as to other family responsibilities, jobs, etc.					
7	I feel that the present situation with my ... does not allow me as much privacy as I'd like.					

Appendix 11 – Approaches to Dementia Questionnaire (ADQ-19)

(Lintern, 2001)

Instructions

Please indicate to what extent you agree or disagree with each of the following statements:

ADQ-19					
	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. It is important to have a very strict routine when working with dementia sufferers.	0	1	2	3	4
2. People with dementia are very much like children.	0	1	2	3	4
3. There is no hope for people with dementia.	0	1	2	3	4
4. People with dementia are unable to make decisions for themselves.	0	1	2	3	4
5. It is important for people with dementia to have stimulating and enjoyable activities to occupy their time.	0	1	2	3	4
6. Dementia sufferers are sick and need to be looked after.	0	1	2	3	4
7. It is important for people with dementia to be given as much choice as possible in their daily lives.	0	1	2	3	4
8. Nothing can be done for people with dementia, except for keeping them clean and comfortable.	0	1	2	3	4
9. People with dementia are more likely to be contented when treated with understanding and reassurance.	0	1	2	3	4
10. Once dementia develops in a person, it is inevitable that they will go down hill.	0	1	2	3	4

11. People with dementia need to feel respected, just like anybody else.	0	1	2	3	4
12. Good dementia care involves caring for a person's psychological needs as well as their physical needs.	0	1	2	3	4
13. It is important not to become too attached to residents.	0	1	2	3	4
14. It doesn't matter what you say to people with dementia because they forget anyway.	0	1	2	3	4
15. People with dementia often have good reasons for behaving as they do.	0	1	2	3	4
16. Spending time with people with dementia can be very enjoyable.	0	1	2	3	4
17. It is important to respond to people with dementia with empathy and understanding.	0	1	2	3	4
18. There are a lot of things that people with dementia can do.	0	1	2	3	4
19. People with dementia are just ordinary people who need special understanding to fulfil their needs.	0	1	2	3	4

Appendix 12 – Short Form Zarit Burden Interview (ZBI-12)

(Zarit et al., 1980)

	Never (0)	Rarely (1)	Sometimes (2)	Quite frequently (3)	Nearly always (4)
Do you feel					
That because of the time you spend with your relative that you don't have					

enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					
That you don't have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative's illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					

Appendix 13 – Quality of the Caregiver Patient Relationship (QCPR): Carer version

(Spruytte et al., 2002)

Please think about your relationship with the person you are caring for.

1. My relative and I often spend time together in an enjoyable way.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

2. My relative and I often disagree..

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

3. There is a big distance in the relationship between my relative and myself.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

4. My relative and I accept each other as we are.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

5. If there are problems my relative and I can usually resolve these easily.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

6. I get on well with my relative.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

7. My relative and I are tender towards each other.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

8. My relative often annoys me.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

9. I feel very good if I am with my relative.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

10. My relative and I often try to impose our opinions on each other.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

11. I blame my relative for the cause of my problems.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

12. My relative and I appreciate each other as people.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

13. My relative does not appreciate enough what I do for him/her.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

14. I am always glad to see him/her if I have not seen him/her for some time.

Totally disagree 1	Disagree 2	Not sure 3	Agree 4	Totally agree 5
--------------------	------------	------------	---------	-----------------

Appendix 14 – The Gain in Alzheimer’s Care Instrument

(Yap, 2010)

	Disagree a lot (0)	Disagree a little (1)	Neither agree nor disagree (2)	Agree a little (3)	Agree a lot (4)
Providing care to my relative has					
a. Helped to increase my patience and be a more					

understanding person					
b. Made me a stronger and more resilient person					
c. Increased my self-awareness, making me more aware of myself					
d. Increased my knowledge and skills in dementia care and more					
e. Helped me grow closer to my relative with dementia					
f. Helped to bond my family closer					
g. Enabled me to better relate to older persons and persons with dementia					
h. Given me deeper insights into the meaning of life and my life's perspective					
i. Helped me grow spiritually (e.g., closer to God and being able to look beyond the material world)					
j. Sparked off altruistic goals in me (e.g., wanting more to help others and contribute to the welfare of others who may be going through similar difficulties)					

Appendix 15 – Feedback from Stakeholders

Feedback for DAC course:

Professional (1):

The course is great and very informative. Under the umbrella slide it seemed that there are only 4 types of dementia. Perhaps you could put a 5th to group the other types. Under stage 4 in mobility section they can also lose all mobility and become bed bound.

Other than this I can't think of anything else.

Professional (2):

What you have done is brilliant and you've covered everything I know, I've worked closely with people with dementia/Alzheimer's and other psychological illnesses in the past, it is so sad watching families trying to come to terms with their loved one's illness and to watch the person with dementia gradually deteriorate.

Informal Caregiver (1):

I think it is amazing that you are researching this area and can see it being of great use to carers.

With regards to the content - I don't have any adaptations. I think it fits well with regards to dementia in general and provides a good overview. I don't think anything needs to be taken out. With regards to the myths - I think you have covered the main ones and think this is an important part, so I'm glad you've included it!

Informal Caregiver (2):

Is there anything you feel needs to be improved? - No, I think the layout and content is really good and it seems like it will be an interesting session.

Do you think we have missed anything important or need to take out of the course? - I don't think anything needs to be taken out, all the information is really helpful. Being a carer I think you have covered everything that I can think of!

With regards to the slide on "common myths" – are these in line with what you have heard/experienced? Do you think we need to add any others? - I've definitely heard these myths and I'm glad you are including them, because I find people have such misconceptions which can be really detrimental.

I think its amazing that you're looking into this area (I definitely could've done with this!) - good luck! 😊

Person Living With Dementia (1):

I think the content is great! No need to change anything. The myths I feel cover a range (I am sure there are loads more) but you have done a good job of getting the point across and I am glad you included these bits. I understood it well and I wish everyone that cares for people like me get this kind of training. It would help them to understand us so much better. I am really happy that you are both doing this project and wish you the best.

Person Living With Dementia (2):

I think this is a great course! I would have loved for my family to have accessed this at the beginning of my diagnosis. It covers most things that I can think of and it is understandable. No need for any changes! Wish you all the best for your project – It's a great idea and will hopefully help so many!