Miller, Hannah (2022) *Applying the MRC Complex Interventions Framework to identify effective research methods for exploring dementia carer and worker wellbeing.* D Clin Psy thesis.

# Applying the MRC Complex Interventions Framework to identify effective research methods for exploring dementia carer and worker wellbeing

Hannah M. Miller, MA Hons, MSc

Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

School of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

September 2022

# Table of Contents

# List of Tables

# List of Figures

# Acknowledgements

I would like to first thank the dementia nursing staff who took part in this research. I deeply appreciate the time and insights that you shared with me to inform my study, and hope I have done your stories justice. Thanks also go to the research and development staff who provided so much help to get the project running.

A massive thank you goes to my supervisors, Professor Hamish McLeod and Dr Phil Smith. The thoughtful guidance you both provided helped me to run a project that has been both meaningful and manageable within the constraints of DClinPsy research in a pandemic, and I have learned a lot.

I also want to express my gratitude to the Psychological Therapies for Older People team, who have provided a steady platform during my training and supported my research. Particular thanks to Dr Leigh Whitnall and Dr Rachel Cross for your incredible contributions to my research.

I have been so grateful to be surrounded by a cohort of kind, intelligent and thoughtful fellow trainees. We have not had an easy journey, but you have certainly made it easier – through the Zoom hangouts in first year, stress-busting study sessions, and just helping me to find the funny side of things. I am so grateful to Emma for being my research buddy throughout this process. I will miss our regular conversations (and puppy interruptions).

To my family and friends, thank you for putting up with my absenteeism and boring psychology chat. I cannot promise the chat will lessen because I am still (fortunately) deeply passionate about psychology and mental health, but I look forward to fully enjoying more quality time with you all.

Finally, I would not have made it through this journey without the support of my best friend Kathryn, and my partner Andrew. Kathryn, you have continued to be my personal cheerleader throughout this process – I could not have asked for better support. Andrew, you have grounded me through our shared doctoral journeys, and I am so excited to celebrate as we move into the next part of our adventure.

# Chapter 1 – Process evaluation in dementia carer wellbeing interventions: A systematic review using RE:AIM

Prepared in accordance with the author requirements for Alzheimer's & Dementia: Translational Research & Clinical Interventions (https://alz-journals.onlinelibrary.wiley.com/hub/journal/23528737/homepage/author-guidelines)

Authors: Hannah Miller*[ab] (h.miller.1@research.gla.ac.uk), Hamish McLeod [a] (Hamish.McLeod@glasgow.ac.uk), Emma Neilson [ac] (emma.neilson2@nhs.scot).

[a] University of Glasgow Institute of Mental Health and Wellbeing, 1st Floor Admin Building, Gartnaval Royal Hospital, G12 0XH, UK; [b] NHS Lanarkshire Psychological Therapies for Older People, 59 Airbles Road, Motherwell, North Lanarkshire, ML1 2TP, UK; [c] Clinical Psychology for Older People, New Craigs Hospital, Drumossie Unit, 6-16 Leachkin Road, Inverness, IV3 8NP, UK

*Corresponding author

## Abstract

INTRODUCTION:

As rates of dementia increase globally, so does the need of care for people with dementia. A high proportion of dementia care is provided by informal carers (e.g., spouse or other family member), who can experience reduced wellbeing associated with this role. Complex interventions have been developed targeting informal carers, but there is a lack of data regarding the process of implementing these effectively. This systematic review aimed to identify and describe process evaluation of interventions for informal dementia carers.

METHODS:

Studies were eligible if they employed empirical research methods to evaluate the process of implementing psychoeducational interventions linked to reduced carer burden. Studies had to be peer-reviewed full reports published in English. Medline, Embase, PsycInfo, CINAHL and Cochrane CENTRAL were searched using a predefined strategy. Backwards and forward citation searching was carried out with scoped reports. Reports were screened for inclusion with a sub-sample blind co-rated. Quality of reporting in included studies was appraised. Relevant data were extracted, tabulated, and narratively synthesised.

RESULTS:

Twenty reports were included. Most employed quantitative designs; were from the USA; delivering the Resources for Advancing Alzheimer's Caregiver Health (REACH) intervention. Process evaluation methods within each dimension of the RE-AIM framework were identified. The most common dimension identified was evaluation of Implementation; with Maintenance least common. Thematic synthesis identified that most adaptations were to reduce the intensity of interventions for translation.

CONCLUSIONS:

This study identified promising reports of process evaluation for interventions which improve dementia informal carer burden, which can be usefully applied to inform real-world application of the interventions.  There is a need for increased quality of process evaluation reporting, further characterisation of psychosocial intervention components, and demarcation of active components.

***Key words***
Dementia; caregivers; burden; complex interventions; process evaluation; systematic review.

## Introduction

Dementia is a terminal degenerative illness estimated to impact 43.8 million people globally in 2016, a number that continues to grow with populations ageing (Badhiwala et al., 2019). With the progressive impairment of dementia comes a need for care. The Organisation for Economic Co-operation and Development estimated that 40% of dementia care is carried out by informal carers; usually family or sometimes friends (2018). However, research shows that informal dementia carers can experience reduced mental wellbeing related to their role, such as reduced quality of life, burnout, and stress (Farina et al., 2017). Accordingly, research priorities have promoted the need to explore the most effective ways of supporting the wellbeing carers of people with dementia (PwD) who live at home (James Lind Alliance & Alzheimer's Society, 2013).

### ***Complex Interventions and Process Evaluation of Interventions for Dementia Carer Wellbeing***

Interventions aiming to improve informal dementia carer wellbeing can be viewed as 'complex interventions' (Skivington et al., 2021) because they involve different levels of the system of care around the PwD (carer and usually a health or social care service delivering the intervention). These interventions are also complex as they usually invoke different components, such as training for those who deliver the intervention, information provision to the carer, and modelling of different techniques. A systematic review of psychosocial interventions to support the mental health of informal dementia carers was recently published (Wiegelmann et al., 2021). Of 46 high quality randomised controlled trials of interventions, only half were linked to improved carer mental health. This highlighted the need to uncover what works regarding dementia carer interventions.

An important aspect of uncovering what works in complex interventions is 'process evaluation', a methodology which explores how an intervention functions (e.g., how it is implemented and factors which influence this) (Moore et al., 2015). Process evaluation allows research to move beyond trials of efficacy, to bridge the research-treatment gap by evidencing how effective interventions are applied in practice. A recent systematic review of the implementation of interventions for reducing distressed behaviours in PwD (Bennett et al., 2020) successfully identified aspects of process evaluation and identified the need for a similar review within informal carers of PwD. Searches of the current literature base have confirmed that no such review has yet been proposed or published.

### *Current Review*

This review aimed to systematically identify process evaluation in studies of interventions demonstrated to improve the wellbeing of informal dementia carers. For this purpose, we invoked the RE-AIM framework (Glasgow et al., 1999, 2019) which focuses on five dimensions of process evaluation: Reach (to target population), Effectiveness, Adoption (by settings delivering intervention), Implementation (e.g., fidelity, adaptations), and Maintenance (of the intervention). This framework was applied to answer the research question: What is the nature and quality of process evaluation reported in studies of dementia carer wellbeing interventions?

The specific review aims were to:

- Identify and describe the nature of process evaluation used in these studies, in accordance with the RE-AIM framework.
- Describe the quality of process evaluation studies in this area.
- Identify and synthesise barriers, facilitators, and adaptations to the implementation of these interventions.

## Methods

This review examined process evaluation data from qualitative and quantitative studies of interventions targeting the wellbeing of dementia carers. This review draws on the Medical Research Council complex interventions framework (Skivington et al., 2021) and follows PRISMA guidelines for reporting systematic reviews (Page et al., 2021). The protocol for this review was registered on Prospero (CRD42022303722).

### *Eligibility Criteria*

Eligible studies had to meet the following criteria:

- Study design - Studies employing empirical research methods (e.g., controlled trials, timepoint comparison, recognised qualitative methods) to carry out primary research evaluating the intervention.
- Population - Studies recruiting informal carers (e.g., family carers) providing direct care to PwD as the main carer.
- Intervention - Studies applying psychosocial interventions for PwD and/or their informal carers which contain some element of psychoeducation (i.e., information provided about dementia, caregiving, or broader health issues). Psychoeducation identified with reference to the Intervention Taxonomy (Schulz, 2010).
- Outcomes – The intervention had to be associated with statistically significant improvements on formal measures of carer burden within the research project being reported on.
- Process evaluation methods – In addition to demonstrating effectiveness (see Outcomes, above), studies had to demonstrate process evaluation within the scope of at least 1 other RE-AIM framework dimension:
  - Reach - Quantitative calculations of what proportion of the targeted population were reached.
  - Adoption - evaluation of proportion of possible delivering populations or settings who adopted the intervention.

    - Implementation – measurement of treatment adherence/fidelity by delivering populations, empirical evaluation of facilitators and barriers to implementation, or description of adaptations to interventions.
    - Maintenance – evaluation of continued use of intervention after initial delivery.
- Only peer-reviewed records published in English were included.

Studies were excluded if any of the following was true:

- Study design - non-empirical studies, summary reports and secondary research (e.g., reviews, letters, notes, purely descriptive case reports)
- Population - Studies recruiting people providing formal/professional care for PwD (e.g., health professionals in dementia care settings, care home workers), or informal carers who are not the main carer. Studies including conditions other than dementia, where results for any dementia subgroups were not available (e.g., 'neurocognitive disorder').
- Interventions - Studies evaluating interventions which do not contain an element of psychoeducation involving provision of information about dementia or similar. Studies where no intervention has yet been applied.
- Outcomes – studies not demonstrating statistically significantly reduced burden within the research project being reported on.
- Process evaluation methods - Studies which do not include any element of process evaluation (e.g., pure intervention efficacy studies); subjective observations of process (e.g., discussions noting observed barriers); evaluations of dose or cost-effectiveness.
- Records not published in English.
- Records published prior to 2008.

Inclusion for publications on or after 2008 was added as a narrowing criterion to coincide with the publication of the first MRC Complex Interventions Framework (Craig et al., 2008). Psychoeducation within interventions and carer burden were selected as narrowing criteria to clarify focus in comparison of studies due to being the most common type of intervention and wellbeing measure for this population (Wiegelmann et al., 2021).

### ***Information Sources***

This review drew on the search strategy employed for a past related systematic review which also applied the RE-AIM framework (Glasgow et al., 1999), in that case to review implementation of interventions within dementia residential care (Bennett et al., 2021). The following databases were searched:

- MEDLINE, EBSCOhost (1946 to 24th May 2022).
- Embase (1947 to 25th May 2022).
- PsycINFO, EBSCOhost (1967 to 24th May 2022).
- CINAHL (Cumulative Index to Nursing and Allied Health Literature), EBSCOhost (1980 to 25th May 2022).
- Cochrane Central Register of Controlled Trials (CENTRAL) in the Cochrane Library. (1992 to 25th May 2022)

Key reports identified through initial scoping searches were also used to carry out forward and backward citation searching via Web of Science. Any key reports that were not identified through the database searches were added.

Searches were carried out 24th and 25th May 2022, stored on Endnote reference management software, and screened using Rayyan.

### ***Search Strategy***

The Bennett et al (2021) search strategy was adapted to broaden implementation terms to incorporate further process evaluation terms drawn from reports identified through scoping searches. Search terms to select for records including informal carers and measures of their wellbeing were added. The search strategy was reviewed by an expert librarian. The search strategies are included in Appendix 1.1.

### ***Selection Process***

Records were deduplicated using an earlier version of Bramer and colleagues’ (2016) method. Resulting records’ titles and abstracts were screened in an inclusive manner by first author (keeping any records that cannot clearly be excluded), and the second rater was supplied with a random sample of 50 records to carry out blind co-rating. Full texts of the records not clearly excluded from title and abstract were screened for their relevance by first author, and the second rater was supplied with full texts for all records the first was unsure about, alongside a random sample of included and excluded records. Discrepancies between the raters were resolved by discussion.

At title-abstract screening, observed inter-rater agreement was high (94%) and Cohen's (1960) chance-corrected kappa indicated substantial agreement (*k* = .735). Prevalence and Bias Adjusted Kappa (PABAK; Byrt et al., 1993) was calculated to allow for the tendency for skewness in systematic review decisions. Bias was low (0.06), prevalence was expectedly high (-.74), and PABAK indicated good agreement (.88). At full text screening, observed agreement was high (80%), and both Cohen's *k* (.643) and PABAK (.6) were good. Bias was low (-.2) and prevalence was moderate (-.4).

### *Data Collection Process*

Data were extracted from included records using an extraction template. When any of the desired data were not available, authors were emailed to request missing information.

### *Data Items*

Data were extracted for the following aspects of studies:

- The intervention. Where interventions contained multiple components, these were categorised with reference to categories from the psychosocial intervention taxonomy (Schulz, 2010).
- Delivering population and setting.
- Receiving population.
- Method of measuring burden.
- Effectiveness of the intervention for improving carer burden.
- Process evaluation data.

Information was also extracted regarding study identifiers, location, design, recruitment methods and data analysis methods.

### *Study Quality Appraisal*

Studies were appraised using adapted form of the Standards for Reporting Implementation Studies (StaRI) checklist (Pinnock et al, 2017). This checklist is focussed on studies employing implementation strategies to improve intervention uptake, which is a slightly later aspect of Complex Intervention development (Skivington et al., 2021). As such, the checklist was adapted to refocus items on process evaluation (checklist available in Appendix 1.2). The second rater was supplied with a random sample of five records to carry out blind co-rating of study quality.

### *Synthesis Methods*

Data from selected records were narratively synthesised according to the study aims, given the heterogeneity of the studies in terms of interventions and outcomes.

The data from eligible studies was analysed according to the ESRC Guidance on the Conduct of Narrative Synthesis in Systematic Reviews (Popay et al., 2006) using the following steps:

- Developing a preliminary synthesis of findings of included studies by tabulating findings of studies, grouped according to the process evaluation methods they contain within the categories of the RE-AIM framework (Glasgow et al., 1999).
- Exploring relationships in the data by carrying out thematic synthesis to identify barriers, facilitators and adaptations reported across included studies (Thomas & Harden, 2008).
- Assessing the robustness of the synthesis through using results of quality appraisal to inform the weight given to conclusions drawn and checking conclusions with co-authors.

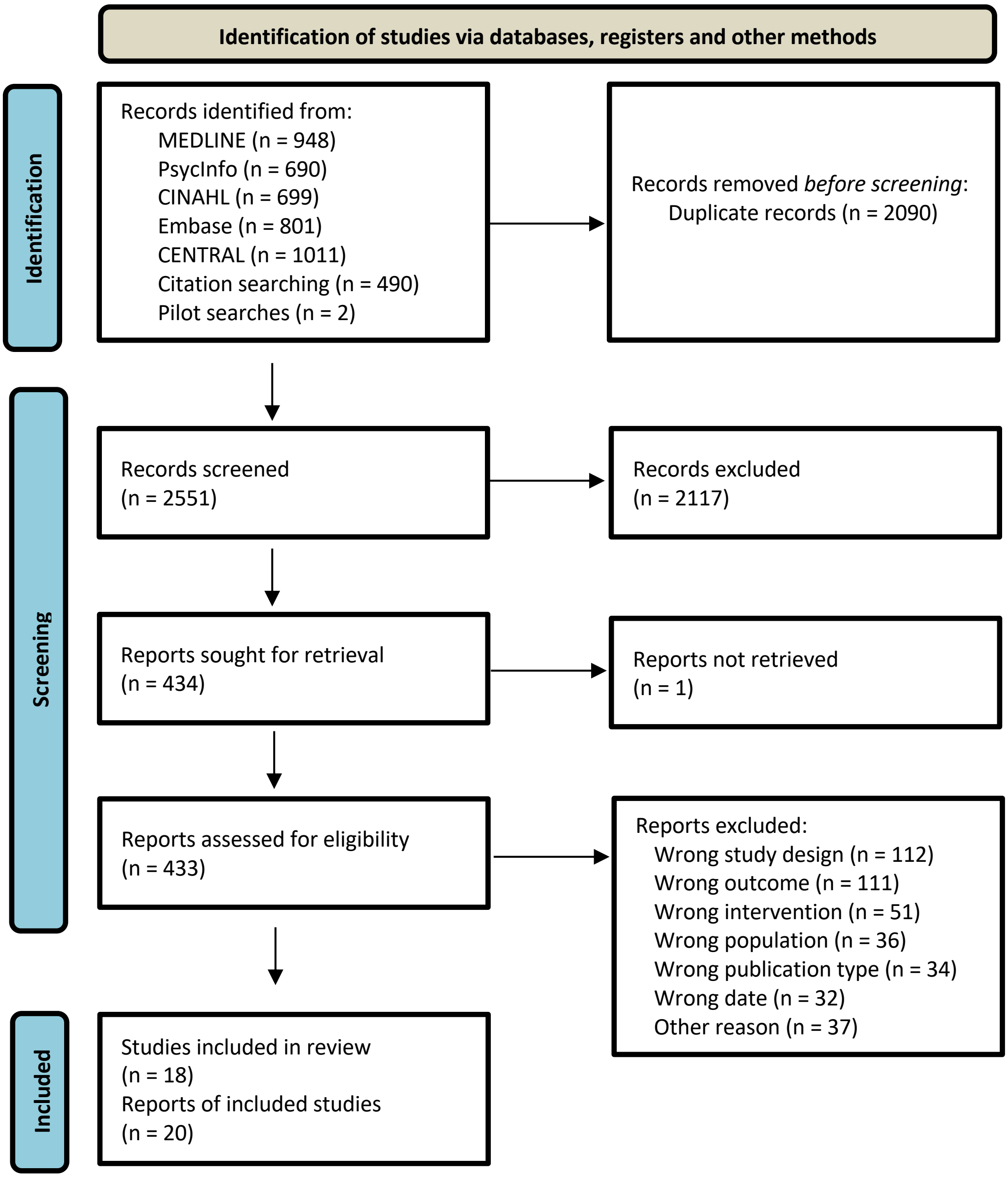
## Results

### *Study Selection*

The electronic search produced 4639 records. Two records identified through scoping that were not picked up through the formal searches were added. The selection outcomes are illustrated in Fig. 1.

**Figure 1.1.**

*PRISMA 2020 Flow Diagram For 'A Systematic Review of Process Evaluations of Interventions Improving Dementia Carer Wellbeing Using the RE:AIM Framework'.*



### ***Study Characteristics***

The characteristics of the included studies are presented in Table 1.1. Of note, the majority employed quantitative designs: nine were uncontrolled pre- and post-treatment evaluations, and six were randomised controlled trials. The majority (11) were carried out in the USA, with an additional two studies carried out online by sites in the USA. Various interventions were implemented, the most common (12) being iterations of the Resources for Advancing Alzheimer's Caregiver Health (REACH).  All interventions were multicomponent, including at a minimum stress-management techniques or behavioural-management techniques, alongside psychoeducation.

**Table 1.1**

*Characteristics of Included Studies*

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| Chiu et al (2009) | Mixed-methods | Canada | Convenience sampling from all families linked to NGO.<br>Purposive sampling for representative sub-sample of 10 for follow-up interviews. | Occupational therapists & social workers developed online information and two provided email communication. | Internet-based Caregiver Support Service (ICSS).<br>Web-based information about dementia and dementia caregiving strategies and local resources.<br>Email correspondence using counselling approach. | Three carers did usability testing. Total of 135 carers identified in organisation; 35 caregivers gave consent, 28 (80.0%) completed intervention. |
| Easom et al (2013) | Pre- and post-test design | USA | Convenience sampling via referral to the program (through self, | Study conducted by university-associated Rosalynn Carter Institute for Caregiving (RCI). | GA REACH.<br>Translation of REACH VA.<br>Up to 9 individual contacts with provider (≤9 home visits and ≤3 | One hundred and sixty-one carers enrolled, |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
|  |  |  | friends, or agency referral). | Seven providers recruited and trained for study due to turnover (three intended). Required high school education and relevant experience and knowledge. | telephone calls) covering set topics (e.g., safety, behavioural issues, caregiver skills and frustrations).<br>Caregiver Notebook (resources and information) provided.<br>Telephone carer support group (≤5 sessions).<br>Contacts guided by manualised scripts. | 85 (53%) completed. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| Hinton et al (2020) | Cluster RCT | Vietnam | Convenience sample of 12 clusters close to study site.<br>Carers identified from records of study site, Vietnam National Geriatric Hospital (NGH). | Providers trained and certified by research team.<br>Providers were healthcare and allied professionals including nurses, physicians, and social workers. | REACH VN. Culturally adapted version of REACH VA.<br>Four 1-hour training sessions for family on education about dementia, problem solving, mood management/ cognitive restructuring, stress management (e.g., signal breath, pleasant event scheduling), and communication, plus ≤2 additional sessions based on carers’ needs and clinical judgment.<br>Mode: telephone, telehealth, or home visit.<br>Control:1 home visit session of education on dementia and safety assessment. | One hundred and forty-eight carers screened,<br>71 eligible,<br>60 randomised.<br>Fifty-one completed. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| Griffiths et al. (2016) | Survey & pre- and post-treatment evaluation | Online / USA | Convenience sample. Referred from local health and social care bodies. | Instructors present in group videoconferences - unclear regarding details. | VA Tele-Savvy. Online translation of Savvy Caregiver Program (SCP).<br>Six-week intervention.<br>Daily internet-delivered video modules on caregiving topics, plus self-care techniques (six per week).<br>Weekly group videoconferences.<br>‘Caregiver manual’ containing information | Thirty carers contacted,<br>22 completed. |
| Kovaleva et al (2019) | Qualitative formative evaluation | Online / USA | Convenience sample. Recruited through online trial recruitment registers, online and hard copy advertisements, | Instructors in group videoconferences - unclear regarding details | Tele-Savvy evaluation. See Griffiths et al (2016), above. | Forty-two carers recruited, 36 caregivers completed intervention and post-program |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| | | | referrals from health care professionals, and word of mouth. | | | interviews. |
| Czaja et al (2018) | Pre- and post-treatment | USA | Not described. | A local non-profit community care organisation. Three staff were trained as providers/ assessors.<br>Staff had minimum bachelor’s degree and experience. | Community REACH.<br>Translation of REACH II.<br>Six-month duration.<br>Twelve 1-hour individual contacts (6 face-to-face and 6 telephone).<br>Five telephone support groups sessions.<br>Targeted: problem behaviours, social support, education and skill building, depression and self-care, and preventive health practices. | One hundred and forty-six carers enrolled, 112 completed 6 months assessment, 94 completed the 12-month follow-up. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| | | | | | Contacts guided by manual. | |
| Kor et al (2019) | Pilot RCT | Hong Kong | Convenience sampling. Recruited through local community centre. Purposive sampling for representative focus group sub-sample | Not described. | Mindfulness-based cognitive therapy group.<br>Ten-week, 7 sessions (2 hours each) including mindfulness activities, psychoeducation on caregiving, and peer sharing session.<br>Control: usual family care seven sessions of education on dementia care. | Forty-six carers interested; 38 eligible; 36 took part. |
| Cho et al (2019) | Pre- and post-treatment | USA | Convenience sampling. Recruitment through referrals from local primary care clinics, home health providers, faith-based | Local community-based dementia organisation. Providers were trained by a co-author. | REACH-TX.<br>Translation of REACH II.<br>6-month intervention with 2-6 home visits and minimum 2 | Fully enrolled 1,522 carers, 1346 provided baseline data, 895 completed |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| | | | organisations, and community agencies. | | telephone calls (number based on risk appraisal).<br>Content included: Safety, Social support, Stress management, Pleasant events, Healthy living, Understanding feelings, Skilful communication, Memory problems and behaviours, Legal and medical information. | follow-up assessment. |
| Nichols et al (2016) | Pre- and post-treatment | USA | Veterans Affairs staff identified stressed and burdened carers on their caseloads, based on their clinical judgment. | Delivered by Veterans Healthcare Administration. Providers included social workers, psychologists, nurses, and other social and behavioural scientists. | REACH VA program phase 2.<br>Adaptation of REACH II. Either: minimum 4 individual sessions over 2-3 months, with additional sessions if required.<br>And/or: telephone support groups. | Enrolled 374 carers, 125 provided eligible outcomes. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| | | | | Minimum of bachelor’s degree. | Including: education, support, and practical skills building (problem solving, communication strategies, cognitive restructuring, and stress reduction).<br>‘Caregiver Notebook’ outlining strategies. | |
| Nehrig & Chen (2019) | Qualitative evaluation | USA | Convenience sample for intervention. Carers referred for intervention by healthcare staff, learned through word-of-mouth or flyers.<br>Purposive sampling of non-responder carers | Eleven providers who provided treatment to the carers included in this study. 1 was a licensed doctoral-level psychologist, 2 postdoctoral psychology fellows, 8 advanced pre-doctoral trainees. All providers trained and | Caregivers were provided with the REACH VA intervention at a VA medical centre.<br>See Nichols et al., (2016), above. | Fifteen non-responder carers out of 24 treatment-completers. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| | | | and their providers for evaluation. | certified in protocol by its developers. | | |
| Stevens et al (2012) | Pre- and post-treatment & implementation evaluation | USA | Not clear. | Setting:1 large hospital (636 beds) and1 large ambulatory internal medicine primary care clinic.<br>Providers: master's-trained counsellors. Unknown number. | Scott & White Family Caregiver Program.<br>Adoption of REACH II.<br>Six-month intervention with 4-5 telephone calls and 0-2 outpatient sessions.<br>‘Caregiver’s Notebook’ of intervention materials, and Family Profile plan of care covering 9 topics: safety, social support, stress management, pleasant events, health, understanding emotions, communication, dementia | Enrolled 164 carers, 72 remained at 6 month follow up. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| | | | | | behaviours, legal & medical information. | |
| Berwig et al (2017) | RCT | Germany | Convenience sampling through outpatient clinic and marketing methods. | Setting: German healthcare system. Required qualification for providers was a three-year health-care traineeship (e.g., occupational therapists, nurses) and experience. | DE-REACH.<br>German translation of REACH-II 12 sessions over 6 months, with 3 telephone sessions.<br>Covered: security, social support, challenging behaviours, emotional wellbeing, self-care & preventative health behaviours. 'Caregiver notebook' and notebook for providers, covering information and resources.<br>Control: usual care e.g. carer counselling, day care, care services. | Enrolled 92 carers, 47 allocated to the intervention and 45 to the control group. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| Cheung et al (2015) | Pre- and post-treatment | Hong Kong | Convenience sampling. NGOs recruited cases from their records or referrals from hospitals and other channels. | Eleven NGOs translating and delivering. Eighty-five providers, registered social workers with experience. Education ranged from associate to master's degrees. | Hong-Kong localised translation of REACH II.<br>12 individual-based sessions, which addressed multiple domains: disease education, home safety, carer health and well-being, care recipients' problem behaviour. Input based on responses on the risk appraisal measure (RAM). | Baseline interview completed by 243 carers;<br>201 completed follow-up interview. |
| Au et al (2019) | Double blinded randomised trial | Hong Kong | Convenience sample. Caregivers recruited while accompanying the care-recipient attending dementia clinics at United Christian Hospital and | One provider with degree in social work delivered all psychoeducation. Six paraprofessional coaches recruited from, and trained by, university-associated | Telephone behavioural activation (BA).<br>Four sessions of psychoeducation adapted from Chinese Version of the Coping with Caregiving manual, covering dementia, stress, pleasant events, communication. | Enrolled 129 carers,<br>111 caregivers randomized,<br>96 available for follow-up. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
|  |  |  | Prince of Wales Hospital. | Institute of Active Ageing. Coaches had an undergraduate degree in helping or service professions. | Eight sessions of BA, reviewing pleasant event work; exploring communication & social support Control group: psychoeducation and general monitoring of caregiving situation. |  |
| Glueckauf et al (2012) | Pre- and post-treatment, two-group comparison pilot study | USA | Targeted convenience sample.<br>Recruited from the records of local memory clinics, through local caregiver organisations, marketing & word of mouth. | African American CBT counsellors. 4 of 9 possible candidates selected. All required to have minimum master's degree in counselling-related profession and minimum 1 year of group intervention experience. All had experience of CBT techniques. | Telephone-based CBT.<br>Remote delivery over provided teleconferencing system.<br>Twelve weekly 1-hr sessions; 7 group and 5 individual.<br>Group sessions covered dementia education, relaxation training, cognitive strategies, wellbeing advice, assertiveness training, managing challenging | Sixteen carers volunteered to participate,<br>2 were not eligible, and 3 withdrew/ dropped out.<br>11 completed. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
|  |  |  |  |  | CG situations and enhancing social support.<br>Individual sessions covered goal-setting, problem-solving and implementation.<br>Control: face-to-face form of intervention |  |
| Tremont et al (2008) | RCT | USA | Convenience sample.<br>Recruited via memory disorder clinics, support groups and newspaper/ television advertisements. | Providers were 2 master's level therapists, trained in the protocol and required to achieve at least 80 percent correct on a test about dementia and the protocol prior to initiating treatment. | Family Intervention: Telephone Tracking - Dementia<br>One-year schedule of 23 telephone calls.<br>Included initial call (orientation and psychoeducation), 6 weekly calls, 12 additional fortnightly contacts, and 4 monthly termination calls. Psychoeducation covered | Enrolled 60 carers (32 assigned to the treatment condition and 28 assigned to standard care); 33 completed 12-month assessment. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| | | | | | information about dementia and common effects of caregiving. The calls providing emotional support, highlighting resources, encouraging self-care, and provision of strategies.<br>Intervention and control both received resource booklet.<br>Control: usual care, no additional intervention. | |
| Burgio et al (2009) | Mixed-methods. Pre- and post-treatment & qualitative program evaluation | USA | Convenience sample. Dyads recruited by local social care agencies via referrals from home health organisations, hospitals, physicians, caseworkers, self- | Led by a partnership formed between the Alabama Department of Senior Services and the University of Alabama. Delivered by local social care agencies, based on a high prevalence of | REACH OUT.<br>Translation of REACH II for local social care agencies.<br>Four home visits and 3 telephone calls.<br>Included risk appraisal. | Baseline was 272 dyads; data available for 236. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
|  |  |  | referral, and outreach. Case managers' clinical judgement about who was invited. | death due to dementia in these areas. | Covered: Education About Dementia, Caregiving, and Stress; Caregiver Health; Home Safety; Behaviour Management; Stress management. |  |
| Kessler et al (2021) | Mixed-methods.<br>Pre- and post-treatment & qualitative program evaluation | USA | Convenience sample. Recruited by clinic providers during patient visits. | Setting: Primary care medical home.<br>All sessions delivered by a Licensed Clinical Social Worker with >20yrs experience. | REACH OUT: Primary Care.<br>Translation of REACH OUT.<br>Sixteen-week program; 6 out-patient group sessions and 5 individual meetings<br>Group sessions offered evidence-based education and skills training.<br>Covered education about dementia, caregiver health, home safety, behaviour management, stress | Screened 33 dyads for eligibility; 7 ineligible, 26 eligible, 1 withdrew before first session, 25 completed baseline measures. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
|  |  |  |  |  | management, and enhancing social support.<br>Individual sessions focused on specific needs of dyads, through using ‘individual Action Plans’. |  |
| Nichols et al (2011) | Pre- and post-treatment translational study | USA | Purposive sample.<br>Primary care staff selected patients and carers who met eligibility criteria. | Setting: Home-Based Primary Care programs, for veterans.<br>Members of staff from 24 facilities in 15 states trained and certified. | REACH VA<br>Translation of REACH II.<br>6-month intervention; 9 1-hour individual home sessions, three 0.5-hour individual telephone sessions, and five 1-hour monthly telephone support group sessions.<br>Covered safety, social support, problem behaviours, depression, and caregiver health. | Enrolled 127 from 24 facilities. Number who declined/ inappropriate unknown. |

| Citation | Study design | Location | Recruitment method | Delivering group | Intervention | Receiving group |
|---|---|---|---|---|---|---|
| Oliveira et al (2021) | Double blind RCT | Brazil | Convenience sample.<br>Participants recruited between August 2015 and May 2018 from different outpatient services through media, radio and television announcements. | Delivered by trained occupational therapists. | Tailored Activity Program.<br>Three-month intervention.<br>Eight face-to-face sessions of up to 1.5 hours.<br>Three phases: 1) assessment of patient abilities and previous abilities, interests, and roles. Carer psychoeducation about dementia symptoms, managing behaviours, and stress reduction; 2) three activities provided with adaptation strategies and instructions for carer; 3) generalisation of adaptive techniques.<br>Control: psycho-education | Screened 86 dyads, 54 included at baseline. |

Note. CBT = Cognitive Behavioural Therapy; NGO = non-governmental organisation; PwD = people with dementia; REACH = Resources Enhancing Alzheimer's Caregiver Health; RCT = randomised controlled trial; VA = Veteran's Affairs.

### ***Quality of Reporting in Studies***

The ratings for studies' quality of reporting according to the adapted StaRI checklist are presented in Table 1.2. Across studies, there was evident background and rationale to the studies; well-described interventions and process evaluation methods; clear evidence of outcomes; and effective discussion of studies' results and process evaluation implications. There were issues in the lack of rationale for sample sizes; poor signposting regarding process evaluation and implementation in titles & abstracts; and a lack of description of the context of the study and populations delivering the intervention.

**Table 1.2**

*Results of Reporting Quality Appraisal With Adapted StaRI Checklist*

| Citation | Title | Abstract | Introduction | Intervention rationale | Study aims | Design | Context | Target providers | Target receivers | PE methods | Intervention description | Sub-groups | Intervention outcome | PE outcome | Sample size rationale | Analysis | Subgroup analyses | Adoption | Reach | Intervention outcome | PE data | Subgroup outcomes | Context change | Harms | Discussion | PE implications | Intervention implications | Statements |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| (Chiu et al., 2009) | ✗ | ✗ | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ? | ? | ✗ | ✓ | ✓ | ✓ | ✓ | N/A | N/A | ✓ | ✓ | ✓ | ? |
| (Easom et al., 2013) | ? | ✗ | ✓ | ✓ | ✗ | ✓ | ✓ | ? | ✓ | ✓ | ✓ | N/A | ✓ | ✗ | ✗ | ✓ | N/A | ✓ | ✓ | ✓ | ✓ | N/A | N/A | N/A | ✓ | ✓ | ✓ | ? |
| (Hinton et al., 2020) | ✗ | ? | ✓ | ? | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | ✓ | N/A | ✓ | ✓ | ✗ | ✓ | N/A | N | ? | ✓ | ✓ | N/A | N/A | ✓ | ✓ | ✓ | ✓ | ✓ |
| (Griffiths et al., 2016) | ✓ | ✗ | ✓ | ✓ | ✓ | ? | ✗ | ✗ | ? | ✓ | ✓ | N/A | ✓ | ✓ | ✗ | ✗ | N/A | ✗ | ? | ✓ | ✓ | N/A | N/A | N/A | ✓ | ✓ | ? | ? |
| (Kovaleva et al., 2019) | ✗ | ? | ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | ✓ | N/A | N/A | ✓ | ✗ | ✓ | N/A | ✗ | ? | N/A | ✓ | N/A | N/A | ✓ | ✓ | ✓ | ? | ✓ |
| (Czaja et al., 2018) | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | N/A | ✓ | ✓ | ✗ | ? | N/A | ? | ? | ✓ | ✗ | N/A | ? | N/A | ✓ | ✓ | ✓ | ✓ |
| (Kor et al., 2019) | ? | ? | ✓ | ✓ | ✓ | ✓ | ✗ | ✗ | ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | ✓ | ✗ | ? | ✓ | ✓ | ? | N/A | ✓ | ✓ | ✓ | ? | ? |

| Citation | Title | Abstract | Introduction | Intervention rationale | Study aims | Design | Context | Target providers | Target receivers | PE methods | Intervention description | Sub-groups | Intervention outcome | PE outcome | Sample size rationale | Analysis | Subgroup analyses | Adoption | Reach | Intervention outcome | PE data | Subgroup outcomes | Context change | Harms | Discussion | PE implications | Intervention implications | Statements |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| (J. Cho et al., 2019) |  | ✓ | ✓ | ✓ | ? | ✓ | ✗ | ? | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | ✗ | ? | ✓ | ✓ | ✗ | N/A | N/A | ✓ | ✓ | ✓ | ? |
| (Nichols et al., 2016) | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ? | ? | ✓ | ✓ | N/A | ✓ | ✓ | N | ✓ | N/A |  | ? | ✓ | ✓ | N/A | ✓ | ✓ | ? | ✓ | ✓ | ? |
| (Nehrig & Chen, 2019) | ✗ | ✗ | ✓ | ✓ | ✓ | ✓ | ✗ | ✗ | ✓ | ✓ | ✓ | N/A | N/A | ✓ | ✓ | ✓ | N/A | ? | ? | N/A | ✓ | N/A | N/A | ? | ✓ | ✓ | ✗ | ? |
| (Stevens et al., 2012) | ✓ | ? | ✓ | ✓ | ? | ? | ✓ | ✓ | ✓ | ✓ | ✓ | N/A | ✓ | ✓ | ✓ | ✓ | N/A | ✓ | ? | ✓ | ✓ | N/A | N/A | N/A | ? | ✓ | ? | ? |
| (Berwig et al., 2017) | ? | ? | ✓ | ✓ | ✓ | ✓ | ? | ? | ✓ | ✓ | ✓ | N/A | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ? | ✓ | ✓ | ✓ | N/A | N/A | ✓ | ✓ | ? | ✓ |
| (Cheung et al., 2015) | ? | ? | ✓ | ✓ | ? | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | N/A | ✓ | ✓ | ✗ | ✓ | N/A | ? | ? | ✓ | ✓ | N/A | N/A | N/A | ✓ | ✓ | ✓ | ? |
| Au et al (2019) | ✗ | ✗ | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | ✓ | ✓ | N/A | ✓ | ✓ | ✓ | ✓ | N/A | ? | ? | ✓ | ✓ | N/A | N/A | ✓ | ✓ | ✗ | ✓ | ? |
| (Glueckauf et al., 2012) | ✗ | ✗ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ | ✓ | ? | ? | ✓ | ✓ | ? | N/A | N/A | ✓ | ✗ | ✓ | ? |

| Citation | Title | Abstract | Introduction | Intervention rationale | Study aims | Design | Context | Target providers | Target receivers | PE methods | Intervention description | Sub-groups | Intervention outcome | PE outcome | Sample size rationale | Analysis | Subgroup analyses | Adoption | Reach | Intervention outcome | PE data | Subgroup outcomes | Context change | Harms | Discussion | PE implications | Intervention implications | Statements |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| (Tremont et al., 2008) | | ✗ | ✓ | ✓ | ✓ | ✓ | ✗ | ? | ✓ | ✓ | ✓ | N/A | ✓ | ✓ | ✗ | ✓ | N/A | ? | ? | ✓ | ✓ | N/A | N/A | N/A | ✓ | ✓ | ✓ | ? |
| (Burgio et al., 2009) | ? | ? | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ? | ✗ | ? | ? | ✓ | ✓ | ? | ✓ | N/A | ✓ | ✓ | ✓ | ? |
| (Kessler et al., 2021) | ? | ? | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ | ✓ | ✓ | N/A | ✓ | ✓ | ✗ | ? | N/A | ? | ? | ✓ | ? | N/A | N/A | ✗ | ✓ | ✓ | ✓ | ? |
| (Nichols et al., 2011) | ? | ? | ✓ | ✓ | ? | ? | ✓ | ? | ✓ | ✓ | ✓ | N/A | ✓ | ✓ | ✓ | ✓ | N/A | ✗ | ? | ✓ | ✓ | N/A | ✓ | N/A | ✓ | ✓ | ✓ | ? |
| (Oliveira et al., 2021) | ✗ | ✗ | ✗ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ | N/A | ✓ | ✓ | ✓ | ✓ | N/A | ? | ? | ✓ | ✓ | N/A | N/A | N/A | ✓ | ✓ | ✓ | ✓ |

### ***Results of Synthesis***

The twenty included reports evaluated aspects of the process of delivering the interventions. Table 1.3 summarises the aspects of process evaluation identified that met the criteria of this review, categorised within the five dimensions of the RE-AIM framework (Glasgow et al., 1999). Studies are reported with those that demonstrated highest reporting quality first. Quantitative process data are described here, and qualitative implementation data synthesis described after.

**Reach.** Two included studies calculated what proportion of the targeted population was reached. A study translating the 'Resources Enhancing Alzheimer's Caregiver Health' (REACH-II) intervention into a hospital and primary care clinic (Stevens et al., 2012) identified 734 eligible PwD with an informal carer in contact with the participating healthcare settings, of whom 164 caregivers (22%) were enrolled, and 72 completed the intervention and assessments (10%). There were no clear issues of reporting quality for this study.

A study of an online carer support intervention (Chiu et al., 2009) targeted all 132 carers who were receiving/awaiting support from the delivering organisation at the time of intervention. Seventy-five percent were sons/daughters of the PwD, and 87.1% were Cantonese speaking. Thirty-five carers enrolled (27%). Twenty-eight carers (21%) completed the intervention, of whom 83% were sons/daughters of PwD. The final proportion of Cantonese speaking carers was not noted, but Mandarin-speakers were significantly less likely to qualify for inclusion, largely due to issues contacting. Sons/daughters were significantly more likely to be eligible for the online service than spousal carers. This report's quality of description was reduced by a lack of clear signposting of process evaluation, and lack of information regarding the delivering population.

**Table 1.3**

*Process Evaluation Data Mapped Onto RE-AIM Dimensions*

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| Chiu et al (2009) | Target population: 132 carers served by local NGO.<br>Study sample: 63 (47.7%) eligible, 35 (55.6% of eligible) consented to taking part.<br>Analysis: Sons/daughters significantly more likely than spouses to be eligible, linked to many spousal carers not having appropriate technology.<br>Expected to recruit more Mandarin-speaking families due to perceived need for support in | Using 28-item Burden Scale for Family Caregivers.<br>Statistically significant change in burden<br>between non-users and frequent users in intent-to-treat analysis ($t$ = 3.15, $df$ = 22, $p$ = 0.005). | | Follow-up interviews identified theme: ‘Needing Help to Access Accounts in an Unfamiliar Portal’. | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| | context of more recent immigrant status.<br>In practice Cantonese-speaking families significantly more likely to be eligible, linked to difficulty contacting Mandarin-speaking families. | | | | |
| Easom et al (2013) | | Using 12-item ZBI.<br>Significantly decreased burden scores from baseline to six-month assessment (*p* = 0.004). | | Adaptations:<br>Increased intervention recruitment efforts.<br>Increased flexibility in mode of contacts | |
| Hinton et al (2020) | | Using 4-item ZBI.<br>Average burden scores significantly lower in intervention group than control group at 3 months (*p* = .02). | | Adaptations:<br>Changes to resources for target culture and literacy level.<br>Increasing time across sessions devoted to caregiver education about dementia.<br>Included other family members. | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| | | | | Weekly rather than biweekly sessions to sustain momentum.<br>Supplemented standard training with Buddhist principles and case-series.<br>Fidelity:<br>Based on treatment checklist completed by providers at each group session.<br>On average, required elements completed for 95% sessions. | |
| Griffiths et al. (2016) | | Using 12-item ZBI.<br>Significant decrease in burden from baseline to post-treatment (*t* = 2.3, *p* < .05, *d* = 0.43). | | Adaptations:<br>Self-directed home learning<br>Virtual groups.<br>Fidelity:<br>Expert rating of consistency of Tele-Savvy compared to the original intervention on scale (−10 to 10; -10 = contains less, 0 = similar, 10 = contains more). | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
|  |  |  |  | All reviewers rated fidelity positively. Only concerns related to “connectedness”. |  |
| Kovaleva et al (2019) |  | See: Griffiths et al., (2016), above. |  | Thirty-six caregivers who completed pilot were interviewed about their experience.<br>Barriers:<br>Online format. Distraction during sessions. Different carer situations (stages, generations). Technical difficulties.<br>Facilitator:<br>Online learning more accessible due to rurality or traffic. |  |
| Czaja et al (2018) |  | Using 12-item ZBI.<br>At six months, carers reported significantly lower overall burden (*g* = .39)<br>At 12 months, effect for burden was maintained. |  | Adaptations:<br>Changed from 9 home-visits and 3 remote sessions to six face-to-face sessions and six telephone sessions.<br>Provision of list of behavioural strategies instead of | Intervention no longer being implemented in full at time of report write-up. Limited implementation related to feasibility potentially reduced by lack of resources. |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| | | | | individualised behavioural prescriptions.<br>Shortened assessment battery.<br>Carers able to receive in-home respite. | |
| Kor et al (2019) | | Using Chinese version of ZBI.<br>Intervention group reported significantly more reduced burden than the control group from baseline to 3-month follow-up ($Z = -2.74$, $p = 0.006$, $d = 1.0$).<br>No significant change in burden for control group. | | Adaptations:<br>Abridging content to reduce length.<br>Weekly telephone follow- up between 5th and 7th sessions to monitor the progress and practice<br>Providing last three sessions bi-weekly instead of weekly for consolidation. | |
| Cho et al (2019) | | Using 12 item ZBI.<br>Significant decrease in burden from baseline to 6-month follow-up ($p < .001$, $d = −0.52$). | | Adaptations:<br>Reduced number of sessions from nine to two-six in-person, depending on risk assessment. | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| | | For participants who enrolled twice, decline in burden from baseline of second enrolment to follow-up was significantly higher than change during first enrolment ($p = .003$). | | Reorganisation of target components in materials into more areas for more user-friendly format. | |
| Nichols et al (2016) | | Using 4-item ZBI.<br>After intervention, carers experienced significant decreases in burden. ($p < .001$, $d = 0.33$) | Original 12-session model: 30 sites trained, 124 staff trained and 85 certified**.**<br>Adapted four-session model: 151 sites trained, 444 staff trained and 265 certified.<br>Analysis: 500% increase. | Adaptations:<br>Reduced from 12 to four sessions<br>Telephone support groups optional, complementary, or standalone<br>Mode of delivery face-to-face, telephone or telehealth. | |
| Nehrig & Chen (2019) | | See: Nichols et al (2016), above | | Barriers:<br>[Perceived by providers] | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
|  |  |  |  | Carer attitudes against accessing support and difficult interpersonal patterns.<br>Lack of ability to tailor material to carer needs.<br>Lack of time to practice skills. |  |
| Stevens et al (2012) | Target population: 734 carers.<br>Study sample: 164 (22%) consented and enrolled, and 72 (10%) completed. | Burden significantly decreased (*p* = 0.002). | All hospital units and clinic care teams fully participated in the intervention.<br>Analysis: 100% adoption. | Adaptations:<br>Intervention materials reformatted into ‘Caregiver's Notebook’ with two additional sections: carer local/national resources and My Family Profile (integration of all intervention components into care plan tailored to needs of the family).<br>Delivery schedule reduced from 12 to four-to-six sessions.<br>In-person sessions in health centre instead of home.<br>Additional awareness-raising training for referrers. |  |
| Berwig et al (2017) |  | Using 22-item German version of ZBI. |  | Adaptations:<br>No structured telephone support group sessions and |  |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| | | Significant treatment-related difference in burden from baseline to post-intervention assessment (*p* < .05, *d* = 0.91).<br>Burden increased in control group. | | specialised computer-integrated telephone system not provided for technical and cost reasons.<br>To compensate for not providing support groups, carers in intervention group were asked to attend local support groups.<br>Adaptation of resources and support to local context.<br>Duration of in-home sessions reduced from 1.5 hours to 1 hour.<br>Bachelor's degree not required for providers. | |
| Cheung et al (2015) | | Using 12-item ZBI.<br>Statistically significant improvement in subjective burden, (*t* = 9.42, *p* = 0.0001) | Eleven NGOs from all 18 districts participated. | Adaptations:<br>No support groups provided due to limited human resources and difficulty integrating with current provisions.<br>Specialised computer-integrated telephone system | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| | | | | not provided due to lack of prevalence.<br>Only first two sessions home-visits, rest at NGO location, due to space limitations and lack of respite. | |
| Au et al (2019) | | Using 22-item ZBI.<br>Carers in the intervention condition significantly lower in burden than control (*t* = -6.84, *p* < .001, *d* = 1.14, [95% CI = -1.54. -0.75]).<br>Burden increased in control group. | | Fidelity:<br>Assessed with provider-rated checklist completed at end of each session, rating how much time spent on components.<br>Behavioural activation providers spent more time on intervention components than psychoeducational components. | |
| Glueckauf et al (2012) | | Using subjective burden subscale of Caregiver Appraisal Inventory. Significantly reduced burden from baseline to | | Fidelity:<br>Two coders blindly rated providers' inclusion of key components of 4 sessions using session-specific fidelity checklists. | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| | | post-treatment (*p* $< .02$, $n^2$partial = .45). | | Average proportion of key components delivered to some extent across all four was .90.<br>Adaptations:<br>Manual adapted to be more representative and accessible.<br>Accessing support of local faith and opinion leaders to sponsor study and recruit.<br>Inclusion of regular newsletter to promote engagement.<br>Use of community locations.<br>Used positively framed project title with biblical reference. | |
| Tremont et al (2008) | | Using 22-item ZBI. Intervention group had significantly lower burden than control group post-treatment. (*p* = .01) | | Adaptations:<br>Lengthened timespan from six to 12 months.<br>Focus on carer.<br>Added social support as key topic covered. | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| Burgio et al (2009) | | Significantly reduced burden post-treatment (*t* = 3.71, *p* = .0001, *d* = .25) | | Adaptations:<br>Removed two treatment components: no specialised computerised-telephone system provided; no provision of social support elicitation training.<br>Reduced time span of intervention.<br>Reduced number of contacts reduced - four home-visits and three telephone contacts.<br>Stress management techniques - reduced to one.<br>Consultation provided on challenging cases.<br>Fidelity:<br>Providers self-rated number of sessions and components delivered on Fidelity Form.<br>On average, 95.2% of the carers received all treatment components during at least 1 session.<br>Barriers:<br>Providers identified issue of | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| | | | | time limitations for implementation. | |
| Kessler et al<br>(2021) | | Using 12-item ZBI.<br>Burden decreased (*p* = 0.006) over the course of the intervention. | | Adaptations:<br>Change of setting – individual & group sessions delivered from primary care setting.<br>Provisions made to support carers to attend - between session telephone support, respite stipend, companion care, and details of local support services. | |
| Nichols et al<br>(2011) | | Using 12-item ZBI.<br>Significantly decreased burden from baseline to 6 months (*p* = 0.001, *d* = 0.33). | | Adaptations:<br>Computer-assisted screen telephones that provided information and facilitated group calls not used due to cost.<br>Provision of list of behavioural strategies instead of individualised behavioural | |

| Citation | Reach | Effectiveness | Adoption | Implementation | Maintenance |
|---|---|---|---|---|---|
| | | | | prescriptions, which would be discussed with provider.<br>Risk appraisal tool shortened. | |
| Oliveira et al (2021) | | Significant reduction in burden in intervention group compared to little change in control (p = 0.01, effect = 0.4) | | Adaptations:<br>Delivered in hospital outpatient setting instead of home-visit.<br>Locally-adapted resource provided. | |

Note. NGO = non-governmental organisation, ZBI = Zarit Burden Interview

**Effectiveness.** It was required for inclusion that all studies demonstrate statistically significant reduction in carer burden in association with the intervention. Eight studies calculated effect sizes using Cohen's d (Cohen, 1992), with values ranging from 0.33 (medium) in a sample of 125 carers (Nichols et al., 2016) to 1.14 (large) in a sample of 96 carers (Au et al., 2019). Focussing on where psychoeducational interventions were used as the control condition, most found that the control group demonstrated a slight reduction in burden (Hinton et al., 2020; Oliveira et al., 2021) or no change (Kor et al., 2019). Psychoeducation plus general monitoring (Au et al., 2019) or provision of a resource booklet only (Tremont et al., 2008) were associated with increased burden.

**Adoption.** Three included studies evaluated the proportion of potential delivering populations who adopted the intervention.

The prior-mentioned REACH primary care translation (Stevens et al., 2012) noted that all units and teams of the hospital and primary care clinic setting participated in the intervention, and so reported 100% adoption on the service level. These findings were supported by high quality reporting of the delivering populations and setting within this report.

A REACH translation for Hong Kong carers (Cheung et al., 2015) identified a high level of adoption due to 11 non-governmental organisations from all 18 districts involved with delivering the intervention. While the quality of reporting was reduced by the inability to identify a clear proportion of organisations involved, this represents a good geographical spread of adoption.

A study implementing REACH for veterans (Nichols et al., 2011) did not provide clear information regarding the delivering population eligibility or characteristics, which limited reporting quality. However, they noted a 503% increase in proportion of delivering settings after moving from the first version of the intervention, a 12-session model (30 sites trained), to the second 4-session model (151 sites). Authors associated the increased uptake with the abbreviation of the intervention, although this was a non-experimental observation and so has limited ability to demonstrate causation.

It should be noted that extraction of data regarding the proportion of intervention adopters from other studies was limited by a general lack of quality reporting of delivering settings and populations, as highlighted in the Adapted StaRI appraisal.

**Implementation.** All studies reported on aspects of 'Implementation', which included fidelity measures, evaluation of implementation barriers and facilitators, and clear documentation of adaptations. Fifteen studies reported implementation data in the form of adaptations to interventions applied to new settings; five reported results of fidelity assessments; and four reported barriers and/or facilitators identified through empirical methods. Results of fidelity assessments are summarised here, and barriers, facilitators and adaptions are synthesised in the next section.

The quality of implementation reporting was good in the following four studies, with clear reporting of intervention components, proposed mechanism of change, and fidelity measurement associated with this. Methods for measuring fidelity to the intervention varied. A study adapting Cognitive-Behavioural Therapy for African-American caregivers included independent rating of four recorded sessions out of the total twelve. They found that 90% of prescribed session components were covered to some extent, which they intepreted as evidence of good fidelity (Glueckauf et al., 2012). Two other studies incorporated interventionist self-rating of components employed in sessions. The first was an evaluation of telephone-based behavioural activation, which found good fidelity to different components of the compared interventions in terms of time spent on each component (Au et al., 2019). The second was a translation of REACH into social care organisations, which found that interventionists delivered 95.2% of the required components for each session on average (Burgio et al., 2009). A translation of the Savvy Caregiver Programme into an online format (Griffiths et al., 2016) evaluated fidelity through expert rating of the adapted intervention components, compared to the original intervention. This method identified that on average, the experts rated most components as having been 'improved upon' by the translation.

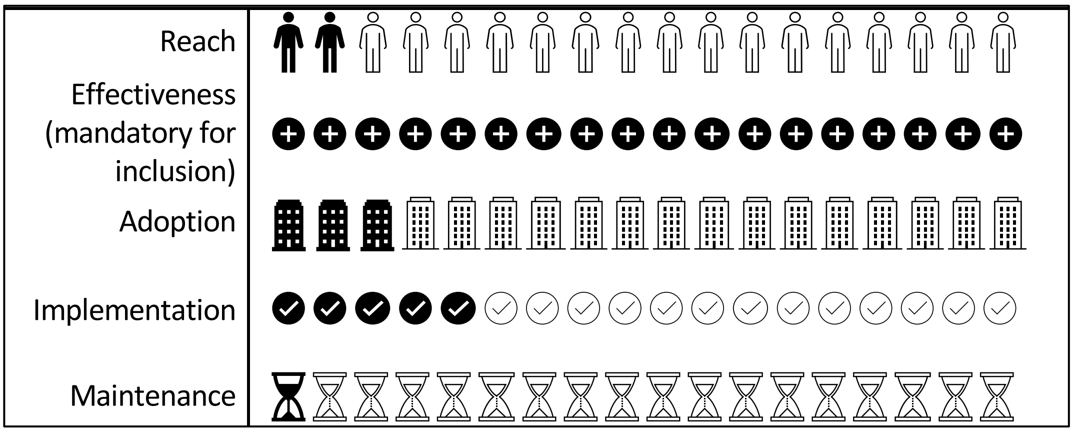
One study's reporting quality was limited by lack of a clear proposed mechanism of change of intervention, and an associated lack of clarity around exactly what aspects must be adhered to. This study, translating REACH for carers in Vietnam, employed interventionist self-rating and found that an average of 95% required components were delivered across sessions (Hinton et al., 2020).

**Maintenance.** One study evaluated continued use of the intervention after initial delivery; a translation of REACH into community delivery settings. Authors found the full intervention was no longer delivered after the trial period (Czaja et al., 2018), which they related to organisational changes and lack of resource. This study had generally good quality of reporting and included information to highlight the implications of the interventions evaluated. One other study noted possible contextual changes which may have impacted study outcomes, but did not provide maintenance data.

The number of studies reporting eligible quantitative data within each dimension of the framework is summarised in Figure 1.2.

**Figure 1.2**

*Number of Studies Reporting Eligible Quantitative Data Within Each RE-AIM Dimension*



### ***Barriers, facilitators, and adaptations thematic synthesis***

Samples of deductive codes applied to study text regarding barriers, facilitators and adaptations can be viewed in Appendix 1.3, and the grouping of these codes in Appendix 1.4.

**Adaptations.** Given the high numbers of adaptations notes across studies, only code groups containing five or more studies are highlighted here.

The most common forms of adaptation were ‘Changes to frequency, number, or length of intervention contacts’, and ‘Changes to materials or resources provided’, both identified in eight studies. '***Changes to frequency, number, or length of intervention contacts***' usually involved a *reduction* in intensity of the intervention (Berwig et al., 2017; Burgio et al., 2009; J. Cho et al., 2019; Kor et al., 2019; Nichols et al., 2016; Stevens et al., 2012). The two exceptions were adapting interventions by increasing frequency of sessions (Hinton et al., 2020) or intervention timespan (Tremont et al., 2008).

**'*Changes to materials or resources provided'*** related to alterations to the content or adjunctive resources provided in the intervention, such as including a pre-selected list of behavioural strategies in the manual instead of developing bespoke behavioural prescriptions in REACH interventions (J. Cho et al., 2019; Czaja et al., 2018; Nichols et al., 2011; Stevens et al., 2012). Other studies did not provide a computer-integrated telephone system that was used for group sessions in the original intervention protocol (Berwig et al., 2017; Cheung et al., 2015; J. Cho et al., 2019; Nichols et al., 2011). These changes highlight pragmatic decisions made to reduce load on the systems implementing these interventions.

Lack of resourcing contributed to some of the adaptations grouped under ***'Added/ removed components of intervention content'***, noted in six studies. Specifically, not having access to the computerised telephone system meant that several REACH implementations did not offer a group component (Berwig et al., 2017; Burgio et al., 2009; Cheung et al., 2015; J. Cho et al., 2019). Components added to the interventions consisted of additional caregiving and self-care techniques (Griffiths et al., 2016), additional psychoeducation (Hinton et al., 2020), or social support as focus area (Tremont et al., 2008).

Six studies provided ***'additional support for receiving population'***. In some cases, this consisted of carers being referred to local pre-existing support groups, as a replacement for the group component (Berwig et al., 2017; Cho et al., 2019). Three studies provided additional contact aside from active intervention sessions, to reduce burden and promote engagement (Glueckauf et al., 2012; Kessler et al., 2021; Kor et al., 2019). Finally, two studies provided respite care for the PwD, to increase access to intervention (Czaja et al., 2018; Kessler et al., 2021). These additions demonstrated ingenious ways to access other resources that could replace hard-to-implement aspects of interventions; and creative ways to promote access and engagement.

**Barriers.** Two studies which trialled online implementation noted '***Accessing online interventions'*** was a barrier due to participants having difficulty using an unfamiliar online platform (Chiu et al., 2009) or due to online delivery impacting sense of connectedness (Kovaleva et al., 2019). Other barriers noted were related to '***Lack of flexibility in provision of input', 'Carer interpersonal difficulties and unprocessed grief'*** (both Nehrig & Chen, 2019), and '***Lack of time'*** (Burgio et al., 2009).

**Facilitators.** The only facilitator of effective implementation identified through evaluation was that '***Online delivery extends reach'*** for some, an alternative perspective identified by participants for whom travel to in-person sessions would have been a barrier in Chiu and colleague's online intervention (2009).

## Discussion

This systematic review explored the nature and quality of process evaluation reported in studies of psychoeducational wellbeing interventions for dementia carers. It identified process evaluation data for each dimension of the RE-AIM framework (Glasgow et al., 1999) across studies. Synthesis of implementation data identified researchers often reduced intervention intensity and resources provided due to human and cost constraints in targeted real-world settings.

**Findings in context**. A previous systematic review of interventions for informal carers (Wiegelmann et al., 2021) identified 13 psychoeducational intervention studies. This contrasts with the identification of 18 intervention effectiveness studies in this review. Comparing differences in studies identified reveals the present review included largely unrelated studies under the umbrella of ‘psychoeducational’ interventions. This aligns with previous evidence that dementia carer interventions are classified inconsistently (Gaugler et al., 2017).

This previous review (Wiegelmann et al., 2021) found that only five of the 13 identified psychoeducational intervention studies significantly reduced carer burden. In contrast, all the studies in this review found reduced burden associated with the intervention. However, it is noted that studies which also tested psychoeducation without additional intervention components failed to demonstrate such significant improvements in burden; while psychoeducation only provided via a booklet or coupled with general monitoring was linked to increased burden. This highlights that psychoeducation alone can be associated with varied outcomes, and the other components of the multicomponent interventions may have been the source of some or all improvement. Coupled with the finding that many studies identified reduced burden despite removing group components of interventions, this raises questions regarding the active components of these interventions. This suggests that these multicomponent interventions could benefit from full dismantling studies to identify what the effective mechanisms of action are.

The high frequency of adaptations to reduce intervention intensity and resources, as well as the lack of ‘Maintenance’, demonstrates that many intervention adapters felt that the targeted intervention sites did not have means to implement the original interventions in full. This aligns with the availability of resources being highlighted as a barrier to implementation of complex interventions in dementia residential care (Groot Kormelinck et al., 2021). These results suggest that although interventions demonstrate positive outcomes in well-resourced clinical trials, they may require further optimisation to be feasibly rolled out in routine care. However, optimisation must be balanced with effectiveness, demonstrated by a lack of time being identified as a barrier to implementation in an intervention adapted to include less sessions.

Half of the identified ‘Implementation’ barriers and facilitators were related to online delivery of interventions. Given that aspects of online delivery were perceived as both a barrier and a facilitator to accessing interventions, this confirms that online delivery can be acceptable, but require careful exploration of how accessible it is in practice for the targeted ‘real-world’ recipient. The barriers identified here demonstrate that additional support may be required to increase recipient competency with online platforms, and enhance their sense of connectivity. This point is particularly pertinent with online delivery of interventions increasing in the context of COVID-19 pandemic (World Health Organization, 2020).

The identification of ‘lack of flexibility’ in manualised interventions being a barrier to effective implementation in this review complements ‘adaptability’ being identified in the dementia residential care interventions review (Groot Kormelinck et al., 2021). These complementary findings highlight a tension in the translation of evidence-based interventions. On one hand, protocolising interventions can be a means of supporting ease of ‘Adoption’ and faithful ‘Implementation’ of the active components of an intervention (fidelity) in delivering populations. On the other hand, employing a tailored, personalised intervention can allow for appropriate accommodations to suit the receiving populations and the implementation context, which may improve ‘Reach’ and ‘Maintenance’. This emphasises why careful measurement and reporting of both adaptations and fidelity are necessary for evaluating the process of translating interventions effectively.

**Limitations**. There were limitations regarding the data from included studies. First, quality appraisal identified a lack of detail relevant to process evaluation in reports. Studies were rarely explicitly labelled as containing ‘process evaluation’ and often did not contain sufficient information regarding context and delivering population to easily evaluate processes. Second, the data largely came from studies in the USA which possibly limits the generalisability of the data to other locations. This review itself was also limited in several ways. First, the synthesis of information regarding interventions was somewhat challenged by lack a taxonomy of intervention components which clear guidance that was applicable to this setting. For this review, ITAX was consulted (Schulz, 2010) but its guidance is somewhat limited. Second, the number of studies identified as reporting data under each RE-AIM dimension may have been skewed by the broader criteria for inclusion of data under 'Implementation', due to this being the focus for synthesis. Third, this review used strict eligibility criteria for inclusion of data within RE-AIM dimensions, such as only incorporating barriers and facilitators identified through primary research methods. Although narrowing was necessary within the scope of this project, it means that potentially useful process evaluation data could have been excluded, such as investigators' own observations regarding barriers and facilitators. On the other hand, the inclusion of process evaluation data mostly identified through primary research methods may present a strength regarding the objectivity of the data. On a positive note, the necessity for narrow criteria came about due to the unanticipatedly high volume of potentially eligible studies when using broader criteria, suggesting there is a substantial level of process data being published in this field.

**Implications**. Regarding research implications, one aspect of the narrowing of process evaluation eligibility criteria for this review was not including cost-effectiveness as a form of process evaluation, a decision made due to this not being included in original RE-AIM framework. However, it was noted that there several studies both included and excluded which used this form of evaluation; as such, there may be scope for a future review to focus on cost-effectiveness of these interventions. The challenges noted in classifying intervention components highlights a need for more work in developing ways of defining intervention components in psychosocial interventions, perhaps akin to the health behaviour change technique taxonomy (Michie et al., 2013).

In terms of clinical implications, the tension identified in this review between the manualisation versus personalisation of interventions can be mindfully considered by balancing knowledge of the active components of interventions (as they are further elucidated) with the needs of the delivering and receiving populations. As such, manualised multicomponent interventions like those reviewed here may be useful additions to the initial stages of stepped/matched-care models of provision to improve the wellbeing of informal carers of PwD. This review also demonstrates that the intensity (e.g., number of sessions) and provision of resources can be adapted for these interventions (Resources Enhancing Alzheimer’s Caregiver Health) to fit the delivering context, while maintaining positive effects. The positive outcomes of interventions adapted for different populations and locations highlight that they can be suitably translated with appropriate alterations for language and culture, such as translating resources and involving key community figures.

**Conclusions**. This review highlighted a promising range of process evaluation data from studies of psychoeducational interventions improving dementia carer burden. Synthesis of barriers, facilitators and adaptations highlighted interventions were frequently adapted to reduce load on delivering systems, which led to components (such as group aspects) being removed without damaging positive influence on burden. This suggests that active components could be better clarified. Appraisal of reporting quality emphasised the need for clearer reporting of process evaluation. Meanwhile, issues with characterising intervention components promote this as an area for further development. Overall, this review highlights that process evaluation of dementia carer interventions is a maturing area that can benefit future development and translation of interventions for increased benefit.

## References

Au, A., Yip, H. M., Lai, S., Ngai, S., Cheng, S. T., Losada, A., Thompson, L., & Gallagher-Thompson, D. (2019). Telephone-based behavioral activation intervention for dementia family caregivers: Outcomes and mediation effect of a randomized controlled trial. Patient Education and Counseling, 102(11), 2049–2059. https://doi.org/10.1016/j.pec.2019.06.009

Badhiwala, J. H., Wilson, J. R., & Fehlings, M. G. (2019). Statistics on the burden of dementia: need for stronger data. The Lancet Neurology, 18(1), 25–27. https://doi.org/10.1016/S1474-4422(18)30456-3

Bennett, S., Laver, K., MacAndrew, M., Beattie, E., Clemson, L., Runge, C., & Richardson, L. (2021). Implementation of evidence-based, non-pharmacological interventions addressing behavior and psychological symptoms of dementia: A systematic review focused on implementation strategies. International Psychogeriatrics, 33(9), 947–975. https://doi.org/10.1017/S1041610220001702

Berwig, M., Heinrich, S., Spahlholz, J., Hallensleben, N., Brähler, E., & Gertz, H. J. (2017). Individualized support for informal caregivers of people with dementia-effectiveness of the German adaptation of REACH II. BMC Geriatrics, 17(1), 1–13. https://doi.org/10.1186/s12877-017-0678-y

Bramer, W. M., Giustini, D., Jonge, G. B. de, Holland, L., & Bekhuis, T. (2016). De-duplication of database search results for systematic reviews in EndNote. Journal of the Medical Library Association, 104(3), 240–243–240–243. https://doi.org/10.5195/JMLA.2016.24

Burgio, L. D., Collins, I. B., Schmid, B., Wharton, T., McCallum, D., & Decoster, J. (2009). Translating the REACH Caregiver Intervention for Use by Area Agency on Aging Personnel: The REACH OUT Program. Gerontologist, 49(1), 103–116. https://doi.org/10.1093/geront/gnp012

Cheung, K. S. L., Lau, B. H. P., Wong, P. W. C., Leung, A. Y. M., Lou, V. W. Q., Chan, G. M. Y., & Schulz, R. (2015). Multicomponent intervention on enhancing dementia caregiver well-being and reducing behavioral problems among Hong Kong Chinese: A translational study based on REACH II. International Journal of Geriatric Psychiatry, 30(5), 460–469. https://doi.org/10.1002/gps.4160

Chiu, T., Marziali, E., Colantonio, A., Carswell, A., Gruneir, M., Tang, M., & Eysenbach, G. (2009). Internet-based caregiver support for Chinese Canadians taking care of a family member with alzheimer disease and related dementia. Canadian Journal on Aging, 28(4), 323–336. https://doi.org/10.1017/S0714980809990158

Cho, J., Luk-Jones, S., Smith, D. R., & Stevens, A. B. (2019). Evaluation of REACH-TX: A Community-Based Approach to the REACH II Intervention. Innovation in Aging, 3(3), 1–10. https://doi.org/10.1093/geroni/igz022

Cohen, J. (1992). A power primer. Psychological Bulletin, 112(1), 155–159. http://psycnet.apa.org/journals/bul/112/1/155/

Craig, P., Dieppe, P., Macintyre, S., Mitchie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ (Clinical Research Ed.), 337(7676), 979–983. https://doi.org/10.1136/BMJ.A1655

Czaja, S. J., Lee, C. C., Perdomo, D., Loewenstein, D., Bravo, M., Moxley, J. H., & Schulz, R. (2018). Community REACH: An Implementation of an Evidence-Based Caregiver Program. Gerontologist, 58(2), e130–e137. https://doi.org/10.1093/geront/gny001

Easom, L., Alston, G., & Coleman, R. (2013). A Rural Community Translation of a Dementia Caregiving Intervention. Online Journal of Rural Nursing and Health Care, 13(1), 66–91. https://doi.org/10.14574/ojrnhc.v13i1.248

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. Alzheimer's and Dementia, 13(5), 572–581. https://doi.org/10.1016/J.JALZ.2016.12.010/FORMAT/PDF

Gaugler, J. E., Jutkowitz, E., Shippee, T. P., & Brasure, M. (2017). Consistency of dementia caregiver intervention classification: An evidence-based synthesis. International Psychogeriatrics, 29(1), 19–30. https://doi.org/10.1017/S1041610216001514

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

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

Glueckauf, R. L., Davis, W. S., Willis, F., Sharma, D., Gustafson, D. J., Hayes, J., Stutzman, M., Proctor, J., Kazmer, M. M., Murray, L., Shipman, J., McIntyre, V., Wesley, L., Schettini, G., Xu, J., Parfitt, F., Graff-Radford, N., Baxter, C., Burnett, K., … Springer, J. (2012). Telephone-based, cognitive-behavioral therapy for african american dementia caregivers with depression: Initial findings. Rehabilitation Psychology, 57(2), 124–139. https://doi.org/10.1037/a0028688

Griffiths, P. C., Whitney, M. K., Kovaleva, M., & Hepburn, K. (2016). Development and implementation of tele-savvy for dementia caregivers: A department of veterans affairs clinical demonstration project. Gerontologist, 56(1), 145–154. https://doi.org/10.1093/geront/gnv123

Groot Kormelinck, C. M., Janus, S. I. M., Smalbrugge, M., Gerritsen, D. L., & Zuidema, S. U. (2021). Systematic review on barriers and facilitators of complex interventions for residents with dementia in long-term care. International Psychogeriatrics, 33(9), 873–889. https://doi.org/10.1017/S1041610220000034

Hinton, L., Nguyen, H., Nguyen, H. T., Harvey, D. J., Nichols, L., Martindale-Adams, J., Nguyen, B. T., Nguyen, B. T. T., Nguyen, A. N., Nguyen, C. H., Nguyen, T. T. H., Nguyen, T. le, Nguyen, A. T. P., Nguyen, N. B., Tiet, Q. Q., Nguyen, T. A., Nguyen, P. Q., Nguyen, T. A., & Pham, T. (2020). Advancing family dementia caregiver interventions in low- and middle-income countries: A pilot cluster randomized controlled trial of Resources for Advancing Alzheimer’s Caregiver Health in Vietnam (REACH VN). Alzheimer’s & Dementia: Translational Research & Clinical Interventions, 6(1), 1–8. https://doi.org/10.1002/trc2.12063

James Lind Alliance, & Alzheimer’s Society. (2013). Outcomes of the James Lind Alliance Dementia priority setting partnership. https://www.jla.nihr.ac.uk/priority-setting-partnerships/dementia/downloads/Outcomes-of-the-Dementia-PSP-report.pdf

Kessler, A. S., Mock, G., Hendricks, D., Robbins, L., Kaur, H., Potter, J. F., & Burgio, L. D. (2021). Translating the REACH OUT dementia caregiver intervention into a primary care setting: a pilot study. Aging and Mental Health, 25(8), 1483–1492. https://doi.org/10.1080/13607863.2020.1850638

Kor, P. P. K., Liu, J. Y. W., & Chien, W. T. (2019). Effects of a modified mindfulness-based cognitive therapy for family caregivers of people with dementia: A pilot randomized controlled trial. International Journal of Nursing Studies, 98, 107–117. https://doi.org/10.1016/j.ijnurstu.2019.02.020

Kovaleva, M., Blevins, L., Griffiths, P. C., & Hepburn, K. (2019). An Online Program for Caregivers of Persons Living With Dementia: Lessons Learned. Journal of Applied Gerontology, 38(2), 159–182. https://doi.org/10.1177/0733464817705958

Michie, S., Richardson, M., Johnston, M., Abraham, C., Francis, J., Hardeman, W., Eccles, M. P., Cane, J., & Wood, C. E. (2013). The Behavior Change Technique Taxonomy (v1) of 93 Hierarchically Clustered Techniques: Building an International Consensus for the Reporting of Behavior Change Interventions. Annals of Behavioral Medicine, 46(1), 81–95. https://doi.org/10.1007/s12160-013-9486-6

Moore, G., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., Moore, L., O’Cathain, A., Tinati, T., & Wight, D. (2015). Process Evaluation of Complex Interventions: UK Medical Research (MRC) Guidance. BMJ, 350, h1258. https://doi.org/https://doi.org/10.1136/bmj.h1258

Nehrig, N., & Chen, C. K. (2019). How to address the needs of non-responders to REACH VA: a qualitative analysis. Aging and Mental Health, 23(9), 1203–1208. https://doi.org/10.1080/13607863.2018.1484885

Nichols, L. O., Martindale-Adams, J., Burns, R., Graney, M. J., & Zuber, J. (2011). Translation of a dementia caregiver support program in a health care system - REACH VA.

Archives of Internal Medicine, 171(4), 353–359. https://doi.org/10.1001/archinternmed.2010.548

Nichols, L. O., Martindale-Adams, J., Burns, R., Zuber, J., & Graney, M. J. (2016). REACH VA: Moving from translation to system implementation. Gerontologist, 56(1), 135–144. https://doi.org/10.1093/geront/gnu112

OECD. (2018). Care Needed : Improving the Lives of People with Dementia. https://doi.org/10.1787/9789264085107-en

Oliveira, A. M., Radanovic, M., Mello, P. C. H. de, Buchain, P. C., Vizzotto, A. D. B., Harder, J., Stella, F., Gitlin, L. N., Piersol, C. V., Valiengo, L. L. C., & Forlenza, O. V. (2021). Adjunctive Therapy to Manage Neuropsychiatric Symptoms in Moderate and Severe Dementia: Randomized Clinical Trial Using an Outpatient Version of Tailored Activity Program. Journal of Alzheimer's Disease, 83(1), 475–486. https://doi.org/10.3233/JAD-210142

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ, 372. https://doi.org/10.1136/BMJ.N71

Pinnock, H., Barwick, M., Carpenter, C. R., Eldridge, S., Grandes, G., Griffiths, C. J., … Taylor, S. J. C. (2017). Standards for Reporting Implementation Studies (StaRI): Explanation and elaboration document. *BMJ Open*, *7*(4). https://doi.org/10.1136/bmjopen-2016-013318

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. https://doi.org/10.1177/1356389008097871

Schulz, R. (2010). Intervention Taxonomy (ITAX): Describing Essential Features of Interventions (HMC). Health (San Francisco), 34(6), 811–821. https://doi.org/10.5993/ajhb.34.6.15

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., Mcintosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. BMJ, 374, n2061. https://doi.org/10.1136/bmj.n2061

Stevens, A. B., Smith, E. R., Trickett, L. R. A., & McGhee, R. (2012). Implementing an evidence-based caregiver intervention within an integrated healthcare system. Translational Behavioral Medicine, 2(2), 218–227. https://doi.org/10.1007/s13142-012-0132-9

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology, 8, 45. https://doi.org/10.1186/1471-2288-8-45

Tremont, G., Duncan Davis, J., Bishop, D. S., & Fortinsky, R. H. (2008). Telephone-delivered psychosocial intervention reduces burden in dementia caregivers. Dementia, 7(4), 503–520. https://doi.org/10.1177/1471301208096632

Wiegelmann, H., Speller, S., Verhaert, L. M., Schirra-Weirich, L., & Wolf-Ostermann, K. (2021). Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – a systematic literature review. BMC Geriatrics, 21(1), 1–17. https://doi.org/10.1186/s12877-021-02020-4

World Health Organization. (2020). The impact of COVID-19 on mental, neurological and substance use services: results of a rapid assessment.

# Chapter 2 - A mixed-methods feasibility study of methods of obtaining dementia worker wellbeing data

Prepared in accordance with the author requirements for Journal of Clinical Nursing https://onlinelibrary-wiley-com.knowledge.idm.oclc.org/page/journal/13652702/homepage/forauthors.html

Authors: Hannah MILLER[a b] *, Hamish MCLEOD [a], Philip SMITH [b].

[a] University of Glasgow Institute of Mental Health and Wellbeing, 1st Floor Admin Building, Gartnaval Royal Hospital, G12 0XH, UK; [b] NHS Lanarkshire Psychological Therapies for Older People, 59 Airbles Road, Motherwell, North Lanarkshire, ML1 2TP, UK

* Corresponding author: (h.miller.1@research.gla.ac.uk), +44 (0)141 211 3920

## Plain Language Summary

***Title***

A mixed-methods feasibility study of methods of obtaining dementia worker wellbeing data.

***Background***

People with dementia present with distress behaviours which are linked to dementia worker stress and burnout. Burnout is a condition marked by emotional exhaustion, disconnection from clients and a reduced sense of work achievement. Research has found that organisational culture and empathy can influence burnout, but we do not have enough evidence of whether this is true for nursing staff who help people with dementia. Despite the importance of understanding burnout, staff may find it hard to talk about these experiences, and we do not know the best way to gather the views and experiences of staff.

***Aims and questions***

This study aimed to explore whether dementia distress behaviours are linked to high levels of nursing staff burnout. We also investigated whether staff members' ability to empathise, and the culture of their workplace, could be playing a role in that link.

We tried to answer these questions:

- Is experiencing distress behaviours associated with increased burnout?
- What is the influence of empathy and organisational factors on the relationship between distress behaviours and burnout?

We also explored whether a survey was a feasible way of answering these questions by looking at how many staff members responded to the survey and doing interviews to ask about thoughts on taking part in research.

***Methods***

Participants were nursing staff from NHS Lanarkshire dementia wards because they have the highest rate of exposure to distress behaviours. Participants were given study information through email and in-person contact with ward psychologists and asked to opt-in and provide consent. Participants could participate in a survey (completed online or on paper) and/or one-to-one interviews. The survey consisted of self-report questionnaires exploring exposure to distress behaviours, levels of burnout, organisational factors and ability to empathise. Interviews explored staff work experiences and perceptions of participating in research.

### *Main Findings and Conclusions*

The study found that distress behaviours were related to stress and burnout in responses from both the survey and interviews.

Only 20.3% of the staff invited participated in the survey.

Interviewees said:

- they felt their patient work was becoming more complex;
- they experienced stress and delayed exhaustion from managing distress behaviours;
- they did not feel able to respond to distress behaviours with best practice due to wider problems in their work organisation;
- patients were the priority over tasks like research participation;
- that they did not feel connected to wider systems but wanted to share their experiences.

This study demonstrated some of the unique aspects of staff wellbeing in dementia in-patient settings. These understandings can inform the development of interventions that could benefit staff and patients. This study identified that the survey was not an effective method for researching dementia nursing work experiences and wellbeing. In contrast, interviews seemed to give an opportunity to feel heard and share information on potentially sensitive topics.

## Abstract

### *Aims & Objectives*

This study explored relationships between exposure to dementia distress behaviours, and staff burnout, empathy, and perceived organisational factors. It also aimed to evaluate the feasibility of surveys of this topic.

### *Background*

People with dementia present with distress behaviours that correlate with increased dementia worker burnout. Organisational factors and empathy can also influence burnout. There is insufficient research into burnout in dementia in-patient nursing staff. However, this group may be reluctant to discuss these potentially sensitive issues.

### *Design*

This was a mixed-methods triangulation study.

### *Methods*

In-patient dementia nursing staff were invited to participate. Twelve completed a survey of distress behaviours, burnout, empathy, and organisational factors. Seven participated in qualitative interviews regarding perceptions of research and their work experiences. We report descriptive statistics, survey data correlations and interview themes. Quantitative and qualitative results were triangulated.

### *Results*

One in five eligible staff responded to the survey. Exploratory correlations indicated distress behaviours were associated with burnout and poorer organisational perceptions. Themes from interviews highlighted: patient profiles becoming increasingly complex; staff trying to "get on with" managing distress behaviours and experiencing delayed exhaustion; but feeling their ability to provide ideal care was limited by perceived systemic barriers. A theme of less priority for non-clinical activities was identified as a barrier to research, while "feeling unheard" was a facilitator to participating in research.

### *Conclusions*

The links between staff burnout, organisational factors and exposure to dementia distress behaviours was supported in this study. The qualitative findings enrich our understanding of these relationships, and the interaction of organisational factors and empathy. The survey response rates suggest it was not feasible method for dementia nursing staff to share their experiences via survey, possibly due to the sensitivity of these topics and wider systemic factors.

***Keywords***
Dementia; nursing; burnout; empathy; organisational culture; mixed methods.

## Introduction

People with dementia (PwD) can display distress behaviours (DBs) (such as aggression, delusions, or apathy) which communicate an unmet need, that dementia workers can find stressful to manage (James & Moniz-Cook, 2018). Prolonged work stress can lead to the development of ‘burnout syndrome’, marked by emotional exhaustion, depersonalised responses to patients, and reduced sense of work achievement (Maslach & Jackson, 1981). Exposure to DBs has been associated with significantly higher stress and burnout in care home workers (Schmidt et al., 2012). Greater healthcare worker burnout is associated with reduced quality of care (Hall et al., 2016). Therefore, it is crucial to gather data on how dementia worker burnout develops, for the benefit of both dementia workers and PWD.

## Background

### *Systemic Factors Affecting Staff Burnout*

Much of the previous research into DBs and burnout has focussed on a linear relationship between these concepts. A different way to conceptualise factors influencing dementia worker burnout is to view workers as agents within complex adaptive systems (CAS; Chaffee & McNeill, 2007). This recognises that dementia care occurs in a dynamic system with changes influencing multiple levels, where DBs have reverberating effects, contributing to worker stress and burnout, and going on to impact wider factors through non-linear pathways.

This highlights possible recursive interactions between organisational factors and burnout responses, beyond a linear DB-burnout relationship. For example, burnout is associated with increased staff absence/turnover (Peterson et al., 2011) on the organisational level. This may lead to redistribution of tasks across fewer workers to re-establish “equilibrium” within the system. This would lead to reduced staffing resource to meet needs of PwD, thus impacting quality of care and possibly increasing distress. These organisational factors may also influence levels of burnout. A study of dementia care home workers identified that a perceived lack of organisational support in the context of high rates of DBs was associated with increased burnout (Costello et al., 2019).

### *Intra-Individual Factors in Staff Burnout*

The CAS approach also highlights the role of individual agents in contributing to changes which occur within the system. In the context of dementia healthcare systems, worker empathy is a salient intra-individual attribute to consider, as empathic capacity contributes to the ability to provide effective person-centred dementia care (Fazio et al., 2018), and is associated with lower levels of healthcare worker burnout (Wilkinson et al., 2017). This latter finding suggests that burnout is not necessarily a result of having high empathy, contrary to suggestions in early burnout research (Schaufeli et al., 1996). As such, the impact of DBs on a dementia worker's levels of burnout may be mediated by their capacity to empathise with the PwD.

### *Complexity of Exploring In-Patient Dementia Nursing Burnout*

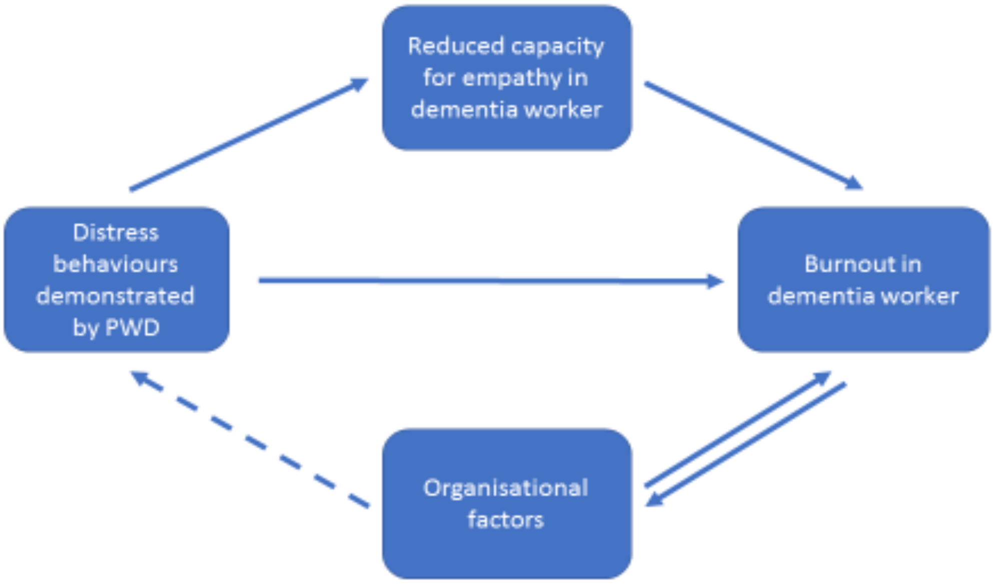
The preceding literature suggests that exposure to DBs can contribute to dementia worker burnout, which can reduce quality of care. However, viewing this issue through a "CAS lens" highlights the need to consider organisational, top-down influences alongside intra-individual, bottom-up influences. Evidence from wider dementia and healthcare workers demonstrates that organisational factors (e.g. perceived lack of support and negative culture) and intra-individual factors (e.g. low empathy) are predictors of burnout. In addition, organisational factors could contribute to increased DBs. However, the relationships between these factors are under-investigated in dementia in-patient nursing staff, and it is not clear how best to gather relevant data on these topics with this population. Nursing staff tend to underreport experiences of workplace violence, possibly due to desensitisation to aggression and minimising some forms of violence as less severe (Lanza et al., 2006). Data that captures the rich interactions between the various elements of these care systems can inform which research methods are feasible for larger scale studies and guide interventions to improve outcomes for workers and patients.

### *The Present Study*

This study explored the relationship between burnout and exposure to DBs, and the possible influence of empathy and organisational factors in a sample of NHS in-patient dementia nursing staff. Given the possible sensitivity and complexity of these issues, the work also examined which research methods were feasible for exploring dementia in-patient nursing experiences. This knowledge will lay the groundwork for developing effective interventions within complex dementia care systems. As such, this study falls within the 'development' and 'feasibility' stages of complex intervention research (Skivington et al., 2021). It contributes to 'development' by examining possible processes in dementia nursing staff burnout, modelled in Figure 2.1 (below); and to 'feasibility' by evaluating participation in research into these topics. In addition, descriptive data regarding the status and impact of the COVID-19 pandemic were collected to contextualise results, given its ongoing impact on older adult care systems at the time of data collection.

**Figure 2.1**

*Suggested Model of Relationships for the Current Study*



*Note.* PWD = Person with dementia. Arrows demonstrate possible relationships of influence identified from previous studies cited above.

**Aims**

Mixed-method aims:

- To explore the relationships in the proposed model (Fig. 1)
    - Is experiencing DBs associated with increased burnout?
    - What is the influence of empathy and organisational factors on the strength of the relationship between experiencing DBs and burnout?

- To explore the feasibility of using survey methods to research dementia nursing staff burnout and work experiences.

Quantitative aim:

- To estimate response rate for future surveys with this population.

Qualitative aim:

- To explore what barriers this population experience to participating in surveys of their experience.

## Methods

### *Study Design*

This study employed a mixed-methods triangulation design (Creswell & Plano-Clark, 2007) to meet the stated aims. Quantitative and qualitative data collection were carried out in one phase, with data analysed separately and then interpreted together descriptively. This was a feasibility study aiming to contribute to development of targeted interventions (Skivington et al., 2021).

This study was granted ethical approval by the Research Ethics Committee of the University of Glasgow School of Medical, Veterinary and Life Sciences (REF 200200188). The study was sponsored and given management approval by NHS Lanarkshire Research & Development (Appendices 2.1 & 2.2).

The COVID-19 pandemic had a significant impact of the design of this study and the capacity to obtain stakeholder contributions to the design and research approach taken. Infection control measures, social distancing requirements and increased pressures on the target population severely limited the opportunity to engage with stakeholders and led to original plans for a survey design being altered.

All aspects of the study were led by the principal investigator (PI; HMM), who had training and experience in the quantitative and qualitative methods used.

### *Participant Recruitment*

This study recruited nursing staff in patient-facing roles (nurse managers, nurses, clinical support workers) from NHS Lanarkshire in-patient dementia wards.

The study employed convenience sampling. Ward psychologists disseminated information about the study and guidance on how to opt-in to either arm of the study by emailing staff lists, displaying posters in staff areas, and in-person contact.

### *Measures and Materials*

Descriptive information regarding the impact of COVID-19 at the time of the study (such as current infection/fatality rates, and control measures in place) was provided by ward psychologists.

The survey, information sheet and consent forms can be found in Appendix 2.3. The survey included questions regarding demographic questions (gender, age, role, experience), the impact of COVID-19 on their responses, and the following measures:

**Distress Behaviours – Adapted Challenging Behaviour Scale** (CBS; Mallon et al., 2019)**.** This 50-item measure explores workers' perceptions of the frequency of their exposure to, and difficulty managing, 25 DBs. Respondents were provided with a list of behaviours such as "Shouting" and rated "How frequently do you experience this?" on a 5-point scale, and "How difficult is it to cope with" on a 4-point scale. The original form asked respondents to answer regarding their experience of one PwD and was found to have good internal consistency (α = .82 - .87) and moderate validity (Moniz-Cook et al., 2001). It was adapted by Mallon and colleagues to gauge overall staff experience, and the adapted version was used here with the original author's permission. No psychometric properties were reported for the adapted version. The 'Challenge score' was used, a summation of the product of each behaviour's frequency and difficulty rating. This measure is copyrighted. The adapted form of this measure was used and replicated with the permission of the first author of the original form; author permission displayed in Appendix 2.2.

**Staff Burnout - Oldenburg Burnout Inventory** (OLBI; Halbesleben & Demerouti, 2005)**.** The OLBI is a 16-item measure of burnout with demonstrated construct validity (Halbesleben & Demerouti, 2005). Respondents rated on a 4-point scale how strongly they agreed with statements like "There are days when I feel tired before I arrive at work". It has good internal consistency (α = .84; Demerouti & Bakker, 2008).

**Staff Empathy - Abbreviated Interpersonal Reactivity Index** (IRI; Davis, 1983)**.** The IRI is a 28-item measure of empathy, defined as "reactions of one individual to the observed experiences of another" (p.113, Davis, 1983). Construct validity was established (Davis, 1983) and internal consistency is acceptable (α = .71 - .77, Davis, 1980). We used two subscales out of four possible: 'perspective taking' (e.g., "I try to look at everybody's side of a disagreement before I make a decision") and 'empathic concern' (e.g., "I often have tender, concerned feelings for people less fortunate than me"). Respondents rated how well they felt the statements from each scale described them on a 5-point scale.

**Organisational Factors – Healthcare Team Vitality Inventory** (HTVI; Upenieks et al., 2010)**.** The HTVI is a 10-item measure of healthcare staff perceptions of their teams' culture and resources. Respondents rated how strongly they agreed on a 5-point scale with statements (e.g., "I have easy access to the supplies and equipment I need to do my work on this unit"). The authors demonstrated convergent validity with other measures of healthcare workers' perceptions of their organisational setting. It has demonstrated acceptable internal consistency (α = .84; Cope, 2016).

The survey was piloted with 2 volunteers from different professional backgrounds to ensure clarity and to estimate completion time.

**Semi-structured interviews.** Interviews explored participants' experience of and responses to DBs, organisational factors, thoughts on participating in research, and perceived impact of COVID-19 on their responses overall. Discussion was guided by questions from the interview schedule, in Appendix 2.4. This schedule was developed based on that used in a project of a similar scope and design (O'Shea, 2016), and aimed to warm-up with a general discussion of interviewees' roles, before asking about their work experiences (based on the concepts modelled in Figure 2.1), followed by research-focussed discussion.

### *Research Procedure*

Participants were supplied with study information and provided informed consent. Participants were able to complete the survey online on the Jisc Online Surveys platform or in print. Interviews were carried out (and recorded) in person in private rooms within the hospitals containing the participating wards. Optional entry into a prize-draw for one of two £20 shopping vouchers was included as a recruitment incentive.

### *Data Analysis*

Descriptive data regarding demographics, the contemporaneous COVID-19 situation, and response/completion rates are presented with measures of central tendency and dispersion.

**Survey Analysis.** Survey data analysis was carried out on SPSS version 28. Cronbach's alpha was calculated for the survey measures. Effect sizes of relationships in the suggested model (Figure 2.1) were estimated using a correlation matrix of all variables; and partial correlations of DB challenge with burnout, controlling for empathy and organisational factors.  Due to the exploratory nature of these analyses, p-values are not reported or interpreted.

**Interview Analysis.** The PI transcribed interview recordings verbatim before employing reflexive thematic analysis (Braun & Clarke, 2022) through the following iterative steps:

- Familiarisation through re-listening to recordings and re-reading transcripts.
- Coding of transcripts using NVivo 12.0 and checking transcripts to ensure appropriate coverage by codes.
- Developing initial themes by grouping codes into patterns noticed in the data informed by research questions and developing a mind map of possible relationships.
- Themes were developed and reviewed by comparing initial themes against data tagged in relevant codes, comparing with the full dataset, and sketching another mind map of new perspectives on themes.
- Refining, defining, and naming themes by writing brief theme descriptions to ensure clarity of contribution.
- Writing up themes through adding data extracts and reflections to develop theme descriptions. Research supervision was used to further clarify themes.

This approach was chosen so a critical, constructionist lens could be employed that allowed participants' perspectives to inductively inform theme development, while holding deductive questions in mind raised by the proposed model.  The PI implemented reflective practice throughout analysis and interpretation to increase awareness of their own subjective reactions. An extract of the reflective notes, a coded transcript excerpt and an example of a theme development mind map are available in Appendix 2.5 to demonstrate the analytic process.

Qualitative and quantitative data were integrated by triangulating survey and interview results according to study aims in a joint display table.

### ***Reflexivity***

I (the PI) work within the discipline of clinical psychology, which meant I approached researching nursing staff experiences somewhat tentatively due to possibly being seen as a professional ‘outsider’. However, in interviews I noticed myself empathising with some of the experiences of managing distress from my past experiences as a support worker. My therapeutic training positions me as someone who listens to individual stories in a supportive fashion and without judgement, which may bias me towards the perspective of the individual participants and preclude balanced understanding of the interplay of agents within these systems. I use the first person in reporting reflections within the results section, to position myself and my reactions in relation to the data.

## Results

### *Recruitment*

The survey ran from 8th November 2021, and interviews ran from 11th November 2021. Recruitment closed 28th January 2022. Multiple contacts were made with both wards by the recruiting ward psychologists across both sites.

Seventeen participants completed the study. Twelve completed the survey and seven completed interviews. Two people completed both arms. The survey took 17 minutes to complete on average, and interviews took 16 minutes to complete on average.

### *Survey Results*

**Demographics.** Detailed characteristics are not reported to protect respondents' identities due to small cell sizes (N <5). The respondents were majority female and relatively well-balanced across the four age categories (ranging between 26-35 and 56-65). All respondents were staff grade nurses, primarily permanent. Participants' dementia healthcare experience ranged from 1-5 years, through to more than 10 years.

**COVID-19 Descriptive Data.** During the data collection period, there were at least nine COVID-19 infections and five deaths across both sites. Infection control procedures were in place throughout requiring at minimum, face masks, physical distancing, and restricted visiting. The Omicron variant became prevalent during recruitment. This led to the wards closing to visitors and the PI having to work remotely. At this point recruitment was stopped.

**Response Rate.** At least 59 members of nursing staff were invited to participate via email. Twelve online surveys were returned. Two paper surveys were handed out, but none were returned. The response rate was calculated as 20.3%. This is likely an over-estimate as it is based on staff invited via email, while other members of staff may have received information through posters and word of mouth.

Eight surveys were 100% complete; four responses were incomplete due to an administration error on the online survey leading to part of the CBS being missing. Where possible, data from all respondents were included. Where CBS data were missing for a participant, their data were not used in analyses including CBS scores.

**Survey Measure Data.** Descriptive data were calculated for each measure and is displayed in Table 2.1.

**Table 2.1**

*Descriptive Statistics for Each Survey Measure*

| Measure | N | Internal consistency (Cronbach's alpha) | Mean | Standard deviation | Median | Inter-quartile range |
|---|---|---|---|---|---|---|
| Distress behaviour challenge score (CBS) | 8 | a = 0.91 | 164.9 | ±51.9 | 167.5 | 71-264 |
| Burnout (OLBI) | 12 | a = 0.52 | 3.11 | ±0.28 | 3.12 | 2.25-3.75 |
| Empathy (abbreviated IRI) | 12 | a = 0.51 | 58.25 | ±5.14 | 58 | 50.25-65.75 |
| Organisational factors (HTVI) | 12 | a = 0.84 | 3.38 | ±0.75 | 3.25 | 2.15-4.45 |

*Note.* CBS = Challenging Behaviour Scale; HTVI = Healthcare Team Vitality Inventory; IRI = Interpersonal Reactivity Index; N = number of compete responses for this measure; OLBI = Oldenburg Burnout Inventory.

Due to the small sample size, survey data were not normally distributed so median scores are reported and non-parametric statistical tests used.  This shows that the CBS and the HTVI both had high levels of internal consistency, while the OLBI and the IRI both had mid-range internal consistency likely due to these questionnaires including two subscales measuring different constructs (Taber, 2018). This score (Mdn = 167.5, IQR = 71-264) tended to be in the 'severe' range of challenge associated with DBs (Moniz-Cook et al., 2001).

Burnout score (Mdn = 3.12, IQR = 2.25-3.75) was above the mean score for healthcare workers (Demerouti & Bakker, 2008). Abbreviated empathy total (Mdn = 58, IQR = 50.25-65.75) was above general population mean (Davis, 1980). Mean organisational factor ratings (Mdn = 3.25, IQR = 2.15-4.45) were poorer than those provided by staff in an acute in-patient rehabilitation unit (Cope, 2016).

When asked to what extent participants agreed their responses had been influenced by the COVID-19 pandemic, 33% disagreed or strongly disagreed, 33% were neutral, and 33% agreed or strongly agreed.

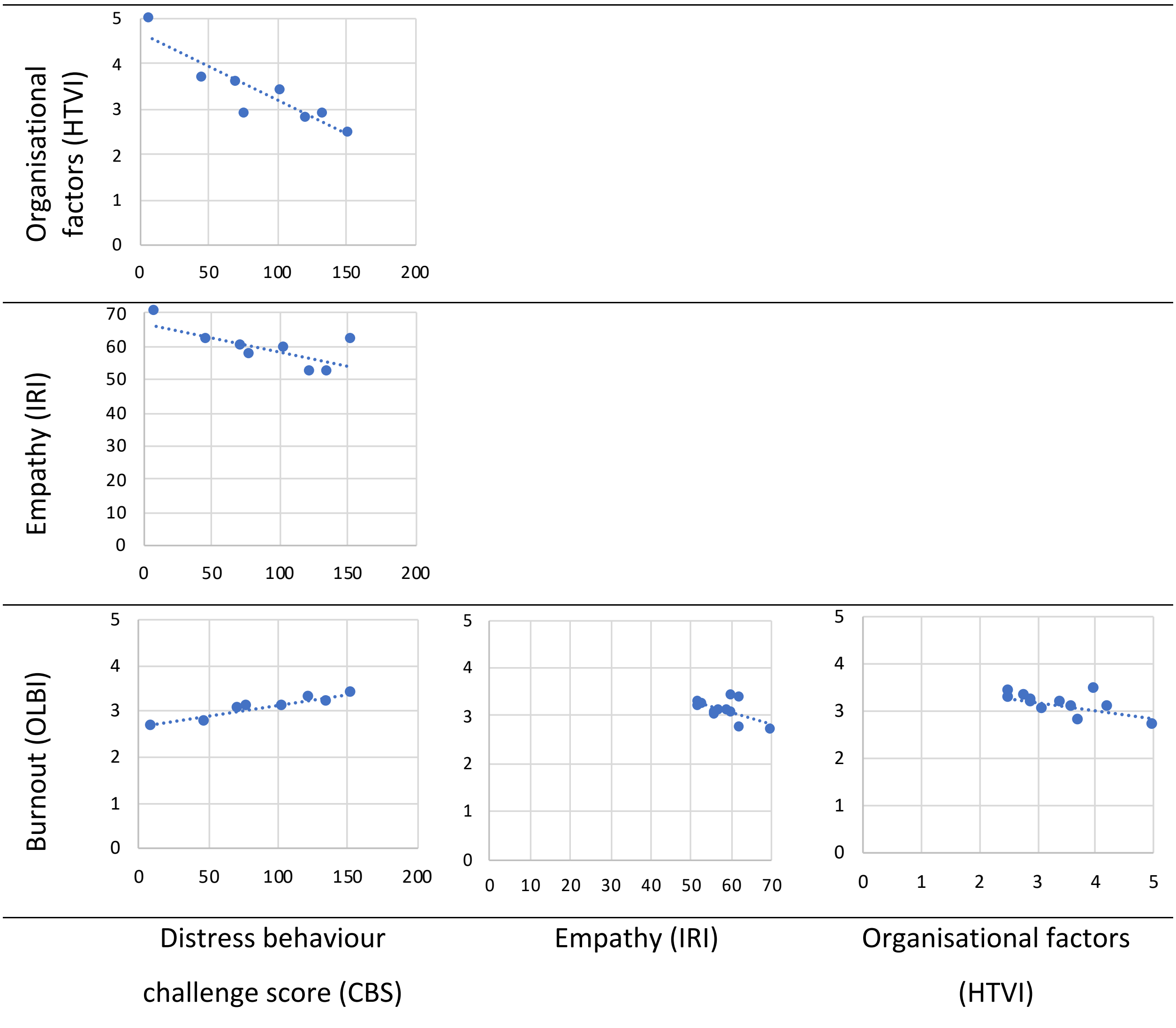
**Exploratory Correlations.** The relationships in Figure 2.1 were explored using non-parametric correlations (Spearman's rho) of survey measures. The relationships of interest between survey measures are visualised in the scatterplot matrix in Figure 2.2, and non-parametric correlation coefficients reported in Table 2.2 with 95% confidence intervals.

As displayed in Figure 2.2 and Table 2.2, the patterns in these preliminary data suggest a positive correlation between DB challenge and burnout, $r_s(6) = .97$, 95% CI [.83, 1] and a negative correlation between DB challenge and organisational factors $r_s(6) = -.92$, 95% CI [-.99, -.60]. There were negative correlations between DB challenge and empathy $r_s(6) = -.54$, 95% CI [-.91, .29], empathy and burnout $r_s(10) = -.32$, 95% CI [-.77, .32], and organisational factors and burnout $r_s(10) = -.58$, 95% CI [-.87, .01]; but these confidence intervals crossed zero. The scatterplots suggest the presence of a ceiling effect on the empathy measure, which may have impacted correlations.

The influence of empathy and organisational factors on the relationship between DB challenge and burnout were explored using partial correlations. The positive correlation between DB challenge and burnout was slightly increased when controlling for empathy, $r_s(5) = .99$, 95% CI [.99, 1]; and organisational factors, $r_s(5) = 1$, 95% CI [1, 1]. However, interpretation is severely limited by the sample size which was significantly below that required for a sufficiently powered analysis. This was demonstrated by a post-hoc estimation of the number of respondents that would have been required to detect a small effect size (Cohen, 1988) of $f^2 = 0.10$ (calculated from adjusted R2 = .09 from Schmidt et al., 2012, converted using formula from Selya et al., 2012) with $\alpha = .05$ and $\beta = .80$ in a multiple regression with three predictors. This calculation, carried out with G*Power 3.1.9.7, predicted the survey would have needed 100 respondents to perform robust statistical tests of the model in Figure 2.1. In addition, the wide confidence intervals for many of the correlational results suggest the coefficients reported here may not be predictive of coefficients in future studies. As such, these results only serve to model patterns that can guide future studies.

**Figure 2.2**

*Scatterplot Matrix of Scores From Survey Measures*



*Note.* CBS = Challenging Behaviour Scale; HTVI = Healthcare Team Vitality Inventory; IRI = Interpersonal Reactivity Index; OLBI = Oldenburg Burnout Inventory.

**Table 2.2**

*Non-Parametric Simple and Partial Correlations of Scores From Survey Measures*

| Compared variables | Control variable | Spearman's rho | 95% confidence intervals | |
|---|---|---|---|---|
| | | | Lower | Upper |
| Distress behaviour challenge score (CBS) & Burnout (OLBI) | None | .97 | .83 | 1 |
| Distress behaviour challenge score (CBS) & Empathy (IRI) | None | -.54 | -.91 | .29 |
| Distress behaviour challenge score (CBS) & Organisational factors (HTVI) | None | -.92 | -.99 | -.60 |
| Empathy (IRI) & Burnout (OLBI) | None | -.32 | -.77 | .32 |
| Organisational factors (HTVI) & Burnout (OLBI) | None | -.58 | -.87 | .01 |
| Distress behaviour challenge score (CBS) & Burnout (OLB) | Empathy (IRI) | .99 | .99 | 1 |
| Distress behaviour challenge score (CBS) & Burnout (OLBI) | Organisational factors (HTVI) | 1 | 1 | 1 |

*Note.* CBS = Challenging Behaviour Scale; HTVI = Healthcare Team Vitality Inventory; IRI = Interpersonal Reactivity Index; OLBI = Oldenburg Burnout Inventory.

***Interview Responses***

The seven interviewees were drawn from both recruitment wards. There was a mixture of males and females, job roles (ranging between clinical support worker, staff nurse and charge nurse) and a range of years of experience (from less than 5 years to over 10 years).

I identified five themes across interviews, under two overarching themes. These are briefly summarised in Table 2.3. Some quotes were shortened by removing repetitions and intrusions, shown with '…'. Additional quote formatting is outlined in the transcription key in Appendix 2.5. The interview schedule can be viewed in Appendix 2.4.

**Table 2.3**

*Theme Summaries*

| Theme name | Brief description |
|---|---|
| Overarching theme – Patients come first | A common thread through different aspects of the interviews was participants prioritisation of patient care. |
| Less priority for non-clinical activities | The prioritisation of patient care meant that participants felt less able to give time to research and activities linked with survey recruitment, like reading emails. |
| "Get on with it" mentality and its impacts | When faced with dementia distress behaviours, participants reported experiencing stress but needing to suppress this to respond effectively. Participants reported exhaustion after work shifts, possibly indicating burnout. |
| Overarching theme – Reactions to perceived systemic influences | Various iterations of how participants perceived wider systemic influences to be impacting them and their work |
| Ideal care limited by systemic pressures | Participants expressed frustration about wider pressures within the system |

| | | |
|---|---|---|
| | | contributing to increased patient distress and preventing ideal care responses. |
| | Pamtient group requiring additional resource | The nature of the patient group on these wards was associated with higher needs. |
| | Feeling unheard and speaking up | Participants reported feeling separated from wider systems and viewed research as means to have their voices heard. |

**Less Priority for Non-Clinical Activities.** One way that participants referenced the narrative of 'Patients come first' was in how they prioritised their scarce time. Participant 2 alluded to a perceived pressure to work quickly when discussing feeling time-constrained with patients: "And I hate feeling pushed for time with patients, and I know that sounds really terrible, to, that we're not, kind of going through everything really quickly" (lines 153-154). There was a general sentiment that the main barrier to completing the survey was lack of time, e.g., "Just, TIME, that's the only barrier" (Participant 3, line 173).

I noted that although only two interview participants had completed the survey, all had been able to take a similar length of time for interviews as that required for the survey. This made me wonder whether interviews were more accessible, despite other demands on their time.

The nature of survey participation was different from interviews. Survey participation required having time to use a computer or sit and complete paper copies, usually while on the ward. Participants expressed that within their limited time there was little space for such administrative tasks, which was identified as a barrier to survey participation by multiple participants: "finding that five minutes sometimes to get on a computer to do stuff like that" (Participant 6, lines 79-80). This appeared to be because such administrative tasks came second to patient care, and research tasks were possibly not seen as part of their roles as highlighted by Participant 3:

> Aw, I'm happy with [participating in research about work], as long as it doesn't take too long… Because I can't, I would like to commit to it, but obviously my patients and my work comes FIRST, you know what I mean? (lines 195-198).

In contrast, interviews being held in a space away from the ward meant that participants were not required to interrupt their research participation to attend to patient needs.

**'Get On With It' Mentality and Its Impacts.** In transcribing and coding the interviews I was struck by how several of the descriptions of immediate reactions to DBs sounded like a fight/flight/freeze stress response, such as:

> I feel like I become more (…) stressed, and more, kind of (-) I don't want to say ON EDGE, because you're not really being ON EDGE, but you're more (-) AWARE, and you're more SENSITIVE to what's going on, what's happening, and (-) I think you just, (quiet) I don't know (louder) I don't know how to explain what I mean, but (-) suppose it can just affect everybody in different ways, and I feel I don't realise until I go HOME, how it's affected me until I'm kind of SPEAKING about it. Even now, when I'm trying to think, I'm like, I don't because, when I'm on the ward, it just, (quieter) I don't know. (louder) I think there's just so many ways I am un- unaware of. (Participant 2, lines 69-76)

In this case, the participant describes experiencing stress and hypervigilance in their attention to the events occurring around them, two aspects of the fight/flight/freeze response. They also reflect that they have difficulty in identifying and verbalising the impact of experiencing DBs, a phenomenon that I observed in other interviews. This difficulty verbalising the impact of DBs despite apparent descriptions of a stress reaction appeared to be due to participants feeling they had to prioritise patient care over tending to their own reactions.

> You have to try and understand, WHY the behaviour is. So if- if I'm being HARMED, if I'm being INJURED, you know, that's not the time to focus on 'poor me that was sore' (laugh)… That's the time to focus on the PATIENT, and how safely I can maintain that person, and what's DRIVING that behaviour… and how we can do something about STOPPING that behaviour. (Participant 1, lines 39-45)

This prioritisation of the patient was necessary to be able to assess and reduce patients' distress. There was a sense that participants had to suppress their own stress to avoid further escalating patient distress and maintain patient safety.

Some participants noted an apparent delayed reaction of this stress, as they sometimes did not feel the impact of stress until they were on a break or after the shift:

> I'm able to COMPARTMENTALISE that a bit at my work, I can get on with it and cope, whereas when I'm off my work, and when I'm HOME, it affects me more, because I find myself falling asleep and things, you know. Whereas I would never do that… I think it's more of a mental DRAIN that I've got, than a physical, it is a physical job as well, don't get me wrong. That's how the stress is affecting ME. I'm not saying that I'm never stressed in my work, of course I am, but because of the role I've got, I tend to (-) like sort of keep it in, and just DEAL with the situations. (Participant 3 lines 76-83)

This impact was often described as a lack of energy and was related by other participants to managing DBs repeatedly. This fits with the idea that cumulative work stress can lead to burnout (Maslach & Jackson, 1981).

**Ideal Care Limited by Systemic Pressures.** Participants identified their ideal responses to patient distress: providing activities, maintaining a low stimulus environment, recognising the patients' interests, one-to-one contact, or specific non-pharmacological techniques. Medication was seen as a last resort for use when other strategies could not sufficiently reduce distress or risk of harm; a belief expressed strongly by some participants:

> As far as I'm concerned, the LAST resort is medication. I still think there's a place for medication, don't get me wrong... In a perfect world, if we've got enough staff on, the patients all sitting with staff, and we'll be doing activities with them, because THAT'S the way to go and that's the future of this kind of nursing. (Participant 3, 100-106)

I was struck by the care that was evident in many participants' descriptions of their ideal response to distress. There was a clear desire to recognise patients as individual, help them to feel less distressed, and empathise with difficulties as experienced by PwD.

Despite participants' clear preference for employing non-pharmacological approaches for managing DBs, they reported that systemic pressures meant that they lacked (time and human) resources to take these approaches. These systemic pressures included a lack of appropriate staff numbers and skill mix, high numbers of patients and COVID, and providing care that was not aligned with the ideal: "Even although it's perceived you have enough staff, you do NOT have enough staff. So, the limitations there, are, it's maintaining everybody's safety, so we will not necessarily meet that person's needs, but we will keep them SAFE" (Participant 1, lines 193-141)

There was a sense that the systemic issues experienced on the ward were associated with increased patient distress directly (e.g., being fed up due to lack of staff time when understaffed) or indirectly (through lack of personal contact due to infection control measures; or a 'domino effect' of distress due to large numbers of patients in the ward).

> I think the patients are actually suffering because of our lack of staff. We're too busy trying to get all our DUTIES done, don't have the time to put off and to help these people, to kind of, pass their day. They must get fed up with us saying, go and sit down, go up to your bedroom, because we're trying to prevent them INJURING theirself, but they'll come to the desk and they'll pull at the COMPUTER, or they'll throw TEA onto the computer, things like that (Participant 4, lines 75-79)

These systemic barriers also contributed participant discontent due to feeling unable to provide the person-centred care they wanted to: "all this has hampered that a little bit, and it's quite frustrating for us, and I think that's why people ARE a wee bit, I wouldn't say less caring, I would say less (-) they're ON EDGE" (Participant 3, lines 190-193). This sense of being prevented from providing valued forms of care could be conceptualised as external factors reducing self-efficacy and sense of accomplishment in their work, despite participants' knowledge, skills, and high level of care for the patients. Reduced sense of accomplishment is an aspect of burnout syndrome (Maslach & Jackson, 1981).

**Patient Group Requiring Additional Resource.** Participants reflected on the changing profile of patients; more severe DBs and complex needs than in other care settings and in previous times. There was a sense that wider moves to improve community care mean that PwD are not admitted to in-patient wards until there is a very high level of need or challenge, which compounded stress related to DBs.

> I think in recent years it's became a lot more difficult, with the IMPROVEMENT in kind of care home liaison and community support and there being more kind of, more, kind of SUPPORT in the community. People who are diagnosed with dementia I find are

> able to STAY, at home a lot longer, and they're able to be MANAGED a lot better in the nursing homes, so we tend to, the last few years we tend to get them toward the END of their dementia journey, which unfortunately has left us with the experience of a lot of death. A lot of the patients come into us with GENERAL agitation, or kind of EXTREME distress behaviours. (Participant 7, lines 56-62)

The severity of the difficulties presented by these patients was seen as an additional impediment to participants' ability to respond in their ideal ways to DBs, as the level of impairment was seen to limit the effectiveness of some strategies: "obviously quite a lot of our patients are very ADVANCED, so, (-) there's no point, they won't – not that there's no POINT, but like they don't understand what you're saying, [talking about their interests] doesn't make any difference" (Participant 5, lines 59-61). Such experiences could potentially contribute to reducing self-efficacy in ones' work. There was a sense that the level of resourcing and care models have not shifted to match the requirements of the current patient group, such as staff resources for managing aggression: "I think people really underestimate how PHYSICALLY aggressive, a lot of the patients we get in can be, em. And how, we've not always got the staff, and the STRENGTH, for me" (Participant 2, lines 208-210).

This recognition of the increased severity and complexity of dementia being seen by patients was cited by one participant as a facilitator for the participating in the research survey.

> I think it's a valuable AREA of research, and it's good that it's been highlighted that there's NOT a lot of research. The population as we're all being told is getting older. Even having worked in dementia for so many years, I see TOTALLY different people coming through now… to what I did 10 years ago… 10 years ago you were getting people through with DEMENTIA… No mixed dementia… No stretching out the umbrella that all of these degenerative brain conditions now come with. (Participant 1, lines 148-158)

This theme demonstrates that some of the participants were considering their work in ways that fit with Complex Adaptive Systems approach (Chaffee & McNeill, 2007); looking beyond simple cause-and-effect explanations for the issues experienced in their work and considering how wider processes dynamically impact their work.

**Feeling Unheard and Speaking Up.** Some participants described a sense that their wards were disconnected from wider systems which meant that they felt less supported:

> We're in a BUBBLE, if you're OUTSIDE the bubble there seems to be lots of things that can be accessed in regards to psychology for staff, but I feel like it's not very well KNOWN, or kind of fed DOWN, to us staff (Participant 7, lines 158-160)

This contrasted with the feeling of support within the team reported by Participant 6: "we have got a good team, and I think, that's what's helped, that's really helped a LOT of us through it" (lines 108-109).

This apparent disconnect from wider care systems led to participants feeling like their difficulties were not fully recognised by those outside the ward, and so change could not occur. As such, a desire to be heard and share experiences was a motivating factor for participating in research, as this was seen as a chance to have a say, be listened to, and possibly facilitate changes.

> I think we feel kind of UNHEARD… I just feel like we're so out the way of everything and everyone… and so- when [psychologist] said that there was, like you guys were looking into that, and looking into OUR side, OUR perspective, I thought that was actually brilliant. I'm glad it's being done so that we can get a wee say on how things REALLY are. (Participant 2, 175-183)

I noticed that in both the above quotes, there was a sense of physical and social isolation.

A desire to be heard accurately regarding more sensitive topics may have been another barrier to participating in the survey, as demonstrated by Participant 1's feedback on it:

> Some of the questions I found a bit RESTRICTIVE… just the scale of agree to definitely not or absolutely. Sometimes, especially when you're talking about providing the care of OTHERS… I would strongly agree if I could have added a COMMENT. But I went neutral because I didn't want it to sound, it would have made the [response] sound EXTREME. (Lines 214-224)

The desire to be heard may have played a role in participants not managing to complete the survey. I wondered whether a survey is perceived to give less opportunity to feel heard by another person. Thus, the lack of personal contact in the survey could have been another barrier to participation.

**Impact of COVID-19 pandemic on responses.** Participants provided mixed responses regarding the influence of the pandemic on their responses. Some stated issues they had highlighted had been present prior to COVID, while others felt there had been additional significant influence of the pandemic. The impact of COVID on staffing was noted, and the knock-on effect on the team and patients. The difficulties of providing care while adhering to infection control procedures were also discussed.

### ***Integration of Mixed-Methods Results***

See Table 2.4 for the integration of survey and interview data through joint display.

**Table 2.4**

*Joint Display of Quantitative Results Triangulated With Qualitative Results*

| Research aim | Survey results | Interview results |
|---|---|---|
| Explore whether experiencing DBs is associated with increased burnout. | Suggestive positive correlation between DB challenge and burnout. | Observations of the ‘Patient group requiring additional resource’ highlighted the complexity of patients seen in these settings, including severe DBs. Within the ‘“Get on with it” mentality and its impacts’ theme there was evidence of DBs provoking a stress reaction, and delayed exhaustion from repeatedly managing this stress and the DBs which could be a sign of burnout. |
| Explore whether empathy and organisational factors influence the strength of the relationship between experiencing DBs and burnout. | Controlling for empathy or for organisational factors marginally increased the strength of the correlation between DB challenge and burnout. | The ‘Ideal care limited by systemic pressures’ theme highlighted that participants demonstrate care and empathy for their patients. However, they perceived many organisational barriers (particularly related to staffing and COVID-19 related changes or issues) that were seen to increase patient distress and reduce quality of care. Participants’ empathy appeared to interact with perceived organisational barriers to care (and their impacts), leading to frustration and reduced sense of self-efficacy. |

| | | |
|---|---|---|
| Explore the feasibility of using survey methods to research dementia nursing staff burnout and work experiences. | Survey response rate of 20.3% at most, low compared to similar studies.<br>No paper surveys were returned – paper option for surveys may have been associated with additional barriers to participation. | The ‘Less priority for non-clinical activities’ theme identified that participants prioritised direct patient care, which meant they had less time for administrative tasks. This meant that time spent meeting patient needs, and needing to take administrative time for research participation, were barriers to taking part.<br>The ‘Feeling unheard and speaking up’ theme noted that participants were keen to participate in research to have their experiences heard by wider systems, and that interviews may have facilitated a sense of being heard more than the survey. |

*Note.* DB = dementia distress behaviour; DB challenge = score obtained from measure of DB Intensity and frequency.

## Discussion

This was a mixed-methods study which aimed to explore the relationship between experiences of DBs and burnout for in-patient dementia nursing staff, including the possible role of empathy and organisational factors. In addition, this study investigated the feasibility of using survey methods to explore these relationships, given the possible difficulties this population might experience with sharing this information. The results provide preliminary support for moving beyond linear perspectives of burnout in dementia in-patient nursing staff, to multifactorial models like the model proposed in Figure 2.1. Data reflected the complex interactions of individual and systemic factors and adaptations, which supports the use of CAS approaches (Chaffee & McNeill, 2007) to conceptualise dementia in-patient settings. However, quantitative analyses must be interpreted with caution given the very small sample size.

Interview participant reflections on the 'Patient group requiring additional resource' highlighted the increasingly complex profile of patients receiving care in these settings, perhaps related to improved dementia care in the community leading to only the most severe difficulties presenting to wards. This observation regarding community dementia care resources improving is in line with changes to local legislation in recent decades (e.g., Community Care and Health (Scotland) Act, 2002). These complex profiles were linked by interview participants to exposure to more severe DBs, aligning with the severe levels of DBs reported in the survey.

Exploratory correlational analyses suggested higher levels of challenge experienced with DBs were correlated with higher levels of burnout like other dementia worker populations (James & Moniz-Cook, 2018; Schmidt et al., 2012). Some interview participants described emotional and physiological stress responses in response to experiencing DBs, which they suppressed to provide care and safety. Suppressed stress was then followed by exhaustion in time away from work. This exhaustion may suggest staff lack opportunity to enact the necessary 'recovery activities' that help workers to recover and maintain their wellbeing (Sonnentag et al., 2022) and end the stress cycle (Nagoski & Nagoski, 2020), perhaps contributing to the higher-than-average levels of burnout reported by survey respondents.

These contrasting levels of emotional/physiological arousal could be formulated within the organisational ‘Window of Tolerance’ (NHS Education for Scotland (NES), 2019). This model describes the spectrum of arousal from hypoarousal (e.g., exhaustion) to the optimal zone, to hyperarousal (e.g., stress) within teams, and highlights that teams who are fluctuating across this spectrum are demonstrating a normal coping reaction which may impact team culture and performance, which could then reduce the sense of safety conducive to enacting ‘recovery activities’.

Survey respondents reported-higher-than average levels of empathy, possibly leading to a ceiling effect on this measure. A high level of empathy was also evident in how interview participants discussed their patients. Participants clearly articulated the ideal form of care they wanted to provide for patients presenting with DBs, which corresponded with person-centred non-pharmacological practice to meet the underlying need being expressed, as promoted in the Newcastle Model of dementia care (James, 2011). However, participants in both study arms reported systemic issues that interview participants felt constrained their ability to provide this ideal form of care. This could suggest that the apparent association between poorer ratings of organisational factors and higher challenge experienced with DBs in the survey could be linked to patient needs not being met in the context of these constraints. Interview participants also reported frustration at the impact systemic pressures had on patient wellbeing, which could link to exploratory partial correlations suggesting that empathy and organisational factors somewhat influenced the relationship between DB challenge and burnout in survey data.

There were 12 responses to the survey, an estimated response rate of 20.3%. Given that a post-hoc power calculation suggested the survey needed at least 100 respondents to test the proposed relationships, it is evident that future survey studies with this population may need to surmount recruitment challenges to effectively test multi-factor models. The low survey response rate was possibly related to interview participants’ view that they did not have time to take part in research tasks within their time on the ward where time was primarily devoted to patient care above more administrative tasks with ‘Less Priority for Non-Clinical Activities’. This view contrasted with participants’ desire to have their work issues recognised, which appeared to motivate them to participate in interviews despite time constraints.

Participants in both arms of the study disagreed regarding whether the COVID-19 pandemic had influenced their responses. Interview respondents elaborated that the pandemic had certainly affected their work, but for some its influence was insignificant compared to other factors described. It should be noted that the COVID-19 pandemic did impact this project. Direct impacts were the changes to ward contact permissions due to increase of COVID-19 Omicron variant, which was a barrier to recruitment and led to premature termination of data collection. More indirectly, it was observed by ward psychologists that increased staff absence and stress due to COVID-19 limited staff capacity to engage in research, due to reduced human and psychological resources.

These results diverge from some previous findings. The measure of organisational factors in this survey was not correlated with burnout scores, unlike in care home workers (Costello et al., 2019). This may be due to differences in measures of organisational factors used, with the measure used here focused on team culture alongside support. The likely ceiling effect on the survey empathy measure may have hindered the replication of the inverse association between empathy and burnout found in more general healthcare workers (Wilkinson et al., 2017). This ceiling effect may have occurred due to a possible social desirability bias, as it could be expected that nursing staff may feel they must demonstrate empathy for their patients in the course of their work. The survey response rate was much lower than the average response rate for nurses identified in a meta-analysis of surveys with healthcare professionals, 51% (Cho et al., 2013).

The study was limited by the challenges encountered in recruiting participants, partially related to the COVID-19 pandemic, which limits interpretation of the under-powered survey data. Participation in the survey may have been further limited by the demands it presented for any nursing staff who had lower levels of general or computer literacy. The convenience sampling method may have meant participants who were more motivated to participate self-selected, which may have skewed responses regarding research feasibility. Interviewees' responses to questions about the survey and general research participation may have been primed to be more negative by the initial questions centring on difficult work experiences. A sequential mixed-methods design may have been more appropriate to allow time to complete the survey before being invited to interviews exploring survey participation; however, this design was outwith the remit of this project. One participant noted that the lack of free textboxes in the survey meant they felt limited in the ratings they could provide without sounding too “extreme”. Despite these challenges, this study also had various strengths. The mixed-method design facilitated a richer understanding of the questions posed. Participants had a variety of demographic characteristics in both arms of the study, thus a range of perspectives were represented.

This study has implications for how dementia in-patient nursing burnout is modelled and researched. The lack of correlation between organisational factors and burnout, and empathy and burnout, contrasts with previous research findings. Interview data suggested additional factors may be involved in these relationships, such as systemic pressures constraining staff’s sense of efficacy in their roles. The measure of organisational factors explored different constructs (team culture and support) to the organisational factors interview participants referenced (e.g., staff-to-patient ratios and feeling disconnected). This demonstrates the potential usefulness of using stakeholder engagement to identify the measure with most face validity for exploring factors of interest. Finally, this study demonstrated that surveys are not always a feasible means of collecting robust data in this population. The potential limitations noted of using literacy-demanding survey methods in this study highlights that feasibility of future studies could be improved by exploring more accessible ways of gathering data with these populations. This could be improved through clarification of the literacy profile of groups like this, and feasibility work like piloting Plain Language versions of measures with stakeholders to determine the best data acquisition methods (Online Surveys, n.d.). In addition, survey participation appeared to be undermined by the survey being viewed as an additional administrative task that was deprioritised in the context of work pressures on the ward. In contrast, interviews possibly offered a more attractive opportunity to share experiences and have them actively heard, away from sources of stress on the wards. As such, interviews might have been a more ‘sensitive research’ approach (Lanza et al., 2006) which can directly benefit participants, as well as developing the evidence base.

## Conclusion

This study found preliminary evidence of the influence of organisational factors in the association of DBs and burnout among dementia in-patient nursing staff. It also demonstrated challenges in gathering data via survey methods. This population has previously been rarely researched. The variations in these findings compared to past research with similar populations endorses continued focus on this specific subset of the dementia caring population.

## Relevance to clinical practice

This study confirmed previous findings regarding the high level of stress and burnout dementia workers are also present amongst in-patient dementia nursing staff. This presents a clinical need in terms of staff wellbeing. It may be necessary to provide support for staff to practice the necessary recovery tasks, in order to end their stress cycle and prevent burnout. This study also highlighted that organisational factors and highly complex dementia populations limit the ability of staff to provide the best standard of person-centred care, which impacts patients as well as increasing staff distress. Data supported using a complex adaptative systems lens to understand the multiple factors involved in dementia in-patient nursing staff burnout and their ability to provide care, which should be considered in the development of any complex interventions to target these issues.

## References

Braun, V., & Clarke, V. (2022). Thematic analysis: a practical guide. Sage Publications Ltd.

Chaffee, M. W., & McNeill, M. M. (2007). A model of nursing as a complex adaptive system. Nursing Outlook, 55(5), 232-241.e3. https://doi.org/10.1016/j.outlook.2007.04.003

Cho, Y. I., Johnson, T. P., & VanGeest, J. B. (2013). Enhancing Surveys of Health Care Professionals: A Meta-Analysis of Techniques to Improve Response. Evaluation and the Health Professions, 36(3), 382–407. https://doi.org/10.1177/0163278713496425

Cohen, J. (1988). Statistical Power Analysis for the Behavioral Sciences (2nd editio). Routledge. https://doi.org/10.4324/9780203771587

Community Care and Health (Scotland) Act, (2002).

Cope, J. K. (2016). Exploring the Effect of an Interdisciplinary Teamwork Intervention in Acute Rehabilitation [Master of Science, Brigham Young University]. https://scholarsarchive.byu.edu/etd/6459

Costello, H., Walsh, S., Cooper, C., & Livingston, G. (2019). A systematic review and meta-analysis of the prevalence and associations of stress and burnout among staff in long-term care facilities for people with dementia. International Psychogeriatrics, 31(8), 1203–1216. https://doi.org/10.1017/S1041610218001606

Creswell, J., & Plano-Clark, V. (2007). Introducing a mixed method design. In Designing and conducting mixed methods research (1st ed., pp. 58–89). SAGE Publications.

Davis, M. H. (1980). A Mulitdimensional Approach to Individual Differences in Empathy. Journal of Personality and Social Psychology, 44(1), 113–126. https://doi.org/10.1037/0022-3514.44.1.113

Davis, M. H. (1983). Measuring individual differences in empathy: Evidence for a multidimensional approach. Journal of Personality and Social Psychology, 44(1), 113–126. https://doi.org/10.1037//0022-3514.44.1.113

Demerouti, E., & Bakker, A. B. (2008). The Oldenburg Burnout Inventory: A Good Alternative to Measure Burnout (and Engagement). In J. R. B. Halbesleben (Ed.), Handbook of stress and burnout in health care (pp. 65–78). Nova Science Publishers Inc.

Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The Fundamentals of Person-Centered Care for Individuals With Dementia. The Gerontologist, 58(S1), S10–S19. https://doi.org/10.1093/GERONT/GNX122

Halbesleben, J. R. B., & Demerouti, E. (2005). The construct validity of an alternative measure of burnout: Investigating the English translation of the Oldenburg Burnout Inventory. Work and Stress, 19(3), 208–220. https://doi.org/10.1080/02678370500340728

Hall, L. H., Johnson, J., Watt, I., Tsipa, A., & O'Connor, D. B. (2016). Healthcare staff wellbeing, burnout, and patient safety: A systematic review. PLoS ONE, 11(7), 1–12. https://doi.org/10.1371/journal.pone.0159015

James, I. A. (2011). Understanding behaviour in dementia that challenges: A guide to assessment and treatment. Jessica Kingsley Publishers.

James, I. A., & Moniz-Cook, E. (2018). Evidence Briefing: Behaviour that challenges in dementia. https://hull-repository.worktribe.com/output/915932/evidence-briefing-behaviour-that-challenges-in-dementia

Lanza, M. L., Zeiss, R., & Rierdan, J. (2006). Violence against psychiatric nurses: sensitive research as science and intervention. Contemporary Nurse : A Journal for the Australian Nursing Profession, 21(1), 71–84. https://doi.org/10.5172/conu.2006.21.1.71

Mallon, C., Krska, J., & Gammie, S. (2019). Views and experiences of care home staff on managing behaviours that challenge in dementia: a national survey in England. Aging and Mental Health, 23(6), 698–705. https://doi.org/10.1080/13607863.2018.1452898

Maslach, C., & Jackson, S. E. (1981). The measurement of experienced burnout. Journal of Organizational Behavior, 2(2), 99–113. https://doi.org/10.1002/job.4030020205

Moniz-Cook, E., Woods, R., Gardiner, E., Silver, M., & Agar, S. (2001). The Challenging Behaviour Scale (CBS): Development of a scale for staff caring for older people in residential and nursing homes. British Journal of Clinical Psychology, 40(3), 309–322. https://doi.org/10.1348/014466501163715

Nagoski, E., & Nagoski, A. (2020). Burnout. Vermilion.

NHS Education for Scotland. (2019). The Window of tolerance of organisations, services and systems. National Trauma Training Programme Online Resources. https://vimeo.com/377760761

Online Surveys (n.d). *Creating accessible surveys*. Online Surveys. https://www.onlinesurveys.ac.uk/help-support/creating-accessible-surveys/

O'Shea, M. (2016). *Mindfulness-based cognitive therapy for older people in a community setting: a mixed methods feasibility study*. University of Glasgow. Retrieved from https://theses.gla.ac.uk/7588/

Peterson, U., Bergström, G., Demerouti, E., Gustavsson, P., Åsberg, M., & Nygren, Å. (2011). Burnout levels and self-rated health prospectively predict future long-term sickness absence: A study among female health professionals. Journal of Occupational and Environmental Medicine, 53(7), 788–793. https://doi.org/10.1097/JOM.0b013e318222b1dc

Schaufeli, W. B., Dierendonck, D. van, & Gorp, K. van. (1996). Burnout and reciprocity: Towards a dual-level social exchange model. Work and Stress, 10(3), 225–237. https://doi.org/10.1080/02678379608256802

Schmidt, S. G., Dichter, M. N., Palm, R., & Hasselhorn, H. M. (2012). Distress experienced by nurses in response to the challenging behaviour of residents - evidence from German nursing homes. Journal of Clinical Nursing, 21(21–22), 3134–3142. https://doi.org/10.1111/jocn.12066

Selya, A. S., Rose, J. S., Dierker, L. C., Hedeker, D., & Mermelstein, R. J. (2012). A practical guide to calculating Cohen's f 2, a measure of local effect size, from PROC MIXED. Frontiers in Psychology, 3, 111. https://doi.org/10.3389/fpsyg.2012.00111

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., Mcintosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. BMJ, 374, n2061. https://doi.org/10.1136/bmj.n2061

Sonnentag, S., Cheng, B. H., & Parker, S. L. (2022). Recovery from Work: Advancing the Field Toward the Future. Annual Review of Organizational Psychology and Organizational Behavior, 9, 33–60. https://doi.org/10.1146/annurev-orgpsych-012420-091355

Taber, K. S. (2018). The Use of Cronbach's Alpha When Developing and Reporting Research Instruments in Science Education. Research in Science Education, 48, 1273–1296. https://doi.org/10.1007/s11165-016-9602-2

Upenieks, V. v., Lee, E. A., Flanagan, M. E., & Doebbeling, B. N. (2010). Healthcare team vitality instrument (HTVI): Developing a tool assessing healthcare team functioning. Journal of Advanced Nursing, 66(1), 168–176. https://doi.org/10.1111/j.1365-2648.2009.05137.x

Wilkinson, H., Whittington, R., Perry, L., & Eames, C. (2017). Examining the relationship between burnout and empathy in healthcare professionals: A systematic review. Burnout Research, 6, 18–29. https://doi.org/10.1016/j.burn.2017.06.003

# Appendices

## Appendix 1.1 – Search strategies

### *EBSCOhost Medline*

42 **#14 AND #25 AND #32 AND #41**

41 **#33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40**

40 “RE-AIM” N2 (framework OR model OR dimension* OR evaluat*) [Title/Abstract]

39 Cost N2 effectiveness [Title/Abstract]

38 (staff OR carer OR caregiver) N5 (opinion OR satisfaction) [Title/Abstract]

37 Strength* N2 weakness* [Title/Abstract]

36 barrier* N2 (facilitator* OR enabler*) [Title/Abstract]

(research OR Intervention* OR treatment* OR program* OR evidence) N5 (reach OR
adopt* OR uptake OR fidelity OR implement* OR maint* OR Continu* N2 us* OR
35 translat* OR appl* OR adapt*) [Title/Abstract]

34 (process OR program*) N5 evaluat* [Title/Abstract]

33 guideline adherence [MeSH Terms]

32 **#26 OR #27 OR #28 OR #29 OR #30 OR #31**

31 Supporter [Title/Abstract]

30 aide [Title/Abstract]

29 "care assistant" [Title/Abstract]

28 Caregiver [Title/Abstract]

27 Carer [Title/Abstract]

26 "caregivers" [MeSH Terms]

25 **#15 OR #16 OR #17 OR #18 OR #19 #OR #20 OR #21 OR #22 OR #23 OR #24**

24 quality N2 life [Title/Abstract]

23 Mood [Title/Abstract]

22 Anxi* [Title/Abstract]

21 depress* [Title/Abstract]

20 Affect* N2 symptom* [Title/Abstract]

19 Sense N2 competence [Title/Abstract]

18 "Zarit Burden" [Title/Abstract]

17 Subjective N2 burden [Full te Title/Abstract xt]

16 (Carer OR caregiver) N5 (burden OR wellbeing OR stress OR coping) [Title/Abstract]

15 "caregiver burden"[MeSH Terms]

14 **#1 OR #2 OR #3 OR #4 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13**

13 (Parkinson* N2 dementia) OR PDD [Title/Abstract]

12 korsako* [Title/Abstract]

11 binswanger* [Title/Abstract]

10 huntington* [Title/Abstract]

9 creutzfeldt OR jcd OR cjd [Title/Abstract]

8 pick* N2 disease [Title/Abstract]

7 "organic brain disease" OR "organic brain syndrome" [Title/Abstract]

6 lewy* N2 bod* [Title/Abstract]

5 Alzheimer* [Title/Abstract]

4 dement* [Title/Abstract]

3 alzheimer's disease [MeSH Terms]

2 wernicke encephalopathy [MeSH Terms]

1 Dementia [MeSH Terms]

***Ovid Embase search strategy***

1. dementia/
2. Wernicke encephalopathy/
3. Alzheimer disease/
4. ((Parkinson* adj2 dementia) or PDD or korsako* or binswanger* or huntington* or creutzfeldt or jcd or cjd or (pick* adj2 disease) or "organic brain disease" or "organic brain syndrome" or (lewy* adj2 bod*) or alzheimer* or dement*).ab. or ((Parkinson* adj2 dementia) or PDD or korsako* or binswanger* or huntington* or creutzfeldt or jcd or cjd or (pick* adj2 disease) or "organic brain disease" or "organic brain syndrome" or (lewy* adj2 bod*) or alzheimer* or dement*).ti.
5. 1 or 2 or 3 or 4
6. caregiver burden/ or Caregiver Strain Index/ or caregiver burnout/

7. ((Carer or caregiver) adj5 (burden or wellbeing or stress or coping)).ab. or ((Carer or caregiver) adj5 (burden or wellbeing or stress or coping)).ti.
8. (Subjective adj2 burden).ab. or (Subjective adj2 burden).ti.
9. "Zarit Burden".ab. or "Zarit Burden".ti.
10. (sense adj2 competence).ab. or (sense adj2 competence).ti.
11. (affect* adj2 symptom*).ab. or (affect* adj2 symptom*).ti.
12. depress*.ab. or depress*.ti.
13. anxi*.ab. or anxi*.ti.
14. mood.ab. or mood.ti.
15. (quality adj2 life).ab. or (quality adj2 life).ti.
16. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. caregiver/
18. (carer or caregiver or "care assistant" or aide or supporter).ab. or (carer or caregiver or "care assistant" or aide or supporter).ti.
19. 17 or 18
20. ((research or Intervention* or treatment* or program* or evidence) adj5 (reach or adopt* or uptake or fidelity or implement* or maint* or (Continu* adj2 us*) or translat* or appl* or adapt*)).ab. or ((research or Intervention* or treatment* or program* or evidence) adj5 (reach or adopt* or uptake or fidelity or implement* or maint* or (Continu* adj2 us*) or translat* or appl* or adapt*)).ti.
21. (barrier adj2 (facilitator* or enabler*)).ab. or (barrier adj2 (facilitator* or enabler*)).ti.
22. (strength adj2 weakness).ab. or (strength adj2 weakness).ti.
23. ((staff or carer or caregiver) adj2 (opinion or satisfaction)).ab. or ((staff or carer or caregiver) adj2 (opinion or satisfaction)).ti.
24. (cost adj2 effectiveness).ab. or (cost adj2 effectiveness).ti.
25. (RE-AIM adj2 (framework or model or dimension* or evaluat*)).ab. or (RE-AIM adj2 (framework or model or dimension* or evaluat*)).ti.
26. 20 or 21 or 22 or 23 or 24 or 25
27. 5 and 16 and 19 and 26

### *EBSCOhost CINAHL*

S35 S8 AND S19 AND S25 AND S34

S34 S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33

S33 TI Strength* N2 weakness* OR AB Strength* N2 weakness*

S32 TI ( “RE-AIM” N2 (framework OR model OR dimension* OR evaluat*) ) OR AB ( “RE-AIM” N2 (framework OR model OR dimension* OR evaluat*) )

S31 TI Cost N2 effectiveness OR AB Cost N2 effectiveness

S30 TI ( (staff OR carer OR caregiver) N5 (opinion OR satisfaction) ) OR AB ( (staff OR carer OR caregiver) N5 (opinion OR satisfaction) )

S29 TI ( barrier* N2 (facilitator* OR enabler*) ) OR AB ( barrier* N2 (facilitator* OR enabler*) )

S28 TI ( (research OR Intervention* OR treatment* OR program* OR evidence) N5 (reach OR adopt* OR uptake OR fidelity OR implement* OR maint* OR Continu* N2 us* OR translat* OR appl* OR adapt*) ) OR AB ( (research OR Intervention* OR treatment* OR program* OR evidence) N5 (reach OR adopt* OR uptake OR fidelity OR implement* OR maint* OR Continu* N2 us* OR translat* OR appl* OR adapt*) )

S27 TI ( (process OR program*) N5 evaluat* ) OR AB ( (process OR program*) N5 evaluat* )

S26 (MH "Guideline Adherence")

S25 S20 OR S21 OR S22 OR S23 OR S24

S24 TI Supporter OR AB Supporter

S23 TI "care assistant" OR AB "care assistant"

S22 TI caregiver OR AB caregiver

S21 TI carer OR AB carer

S20 (MH "Family Caregiver Status (Iowa NOC)") OR (MH "Caregivers")

S19 S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18

S18 TI quality N2 life OR AB quality N2 life

S17 TI mood OR AB mood

S16 TI Anxi* OR AB Anxi*

S15 TI depress* OR AB depress*

S14 TI Affect* N2 symptom* OR AB Affect* N2 symptom*

S13 TI Sense N2 competence OR AB Sense N2 competence

S12 TI "Zarit Burden" OR AB "Zarit Burden"

S11 TI Subjective N2 burden OR AB Subjective N2 burden

S10 AB ( (Carer OR caregiver) N5 (burden OR wellbeing OR stress OR coping) ) OR TI ( (Carer OR caregiver) N5 (burden OR wellbeing OR stress OR coping) )

S9 (MH "Caregiver Burden") OR (MH "Risk for Caregiver Role Strain (NANDA)") OR (MH "Caregiver Role Strain (Saba CCC)") OR (MH "Caregiver Emotional Health (Iowa NOC)") OR (MH "Caregiver Well-Being (Iowa NOC)") OR (MH "Caregiver Stressors (Iowa NOC)")

S8 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7

S7 TI ( binswanger* OR huntington* OR creutzfeldt OR jcd OR cjd OR (pick* N2 disease) OR "organic brain disease" OR "organic brain syndrome" OR (lewy* N2 bod*) OR alzheimer* OR dement* ) OR AB ( binswanger* OR huntington* OR creutzfeldt OR jcd OR cjd OR (pick* N2 disease) OR "organic brain disease" OR "organic brain syndrome" OR (lewy* N2 bod*) OR alzheimer* OR dement* )

S6 TI korsako* OR AB korsako*

S5 TI PDD OR AB PDD

S4 TI Parkinson* N2 dementia OR AB Parkinson* N2 dementia

S3 (MH "Alzheimer's Disease")

S2 (MH "Wernicke's Encephalopathy")

S1 (MH "Dementia")

### ***EBSCOhost PsycInfo***

S33 S15 AND S16 AND S24 AND S32

S32 S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31

S31 TI ( “RE-AIM” N2 (framework OR model OR dimension* OR evaluat*) ) OR AB ( “RE-AIM” N2 (framework OR model OR dimension* OR evaluat*) )

S30 TI Cost N2 effectiveness OR AB Cost N2 effectiveness

S29 TI ( (staff OR carer OR caregiver) N5 (opinion OR satisfaction) ) OR AB ( (staff OR carer OR caregiver) N5 (opinion OR satisfaction) )

S28 TI Strength* N2 weakness* OR AB Strength* N2 weakness*

S27 TI ( barrier* N2 (facilitator* OR enabler*) ) OR AB ( barrier* N2 (facilitator* OR enabler*) )

S26 TI ( (research OR Intervention* OR treatment* OR program* OR evidence) N5 (reach OR adopt* OR uptake OR fidelity OR implement* OR maint* OR Continu* N2 us* OR translat* OR appl* OR adapt*) ) OR AB ( (research OR Intervention* OR treatment* OR program* OR evidence) N5 (reach OR adopt* OR uptake OR fidelity OR implement* OR maint* OR Continu* N2 us* OR translat* OR appl* OR adapt*) )

S25 TI ( (process OR program*) N5 evaluat* ) OR AB ( (process OR program*) N5 evaluat* )

S24 S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23

S23 TI Supporter OR AB Supporter

S22 TI aide OR AB aide

S21 TI "care assistant" OR AB "care assistant"

S20 TI caregiver OR AB caregiver

S19 TI carer OR AB carer

S18 DE "Caregiving"

S17 DE "Caregivers"

S16 S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14

S15 S1 OR S2 OR S3 OR S4

S14 TI quality N2 life OR AB quality N2 life

S13 TI mood OR AB mood

S12 TI Anxi* OR AB Anxi*

S11 TI depress* OR AB depress*

S10 TI Affect* N2 symptom* OR AB Affect* N2 symptom*

S9 TI Sense N2 competence OR AB Sense N2 competence

S8 TI "Zarit Burden" OR AB "Zarit Burden"

S7 TI Subjective N2 burden OR AB Subjective N2 burden

S6 TI ( (Carer OR caregiver) N5 (burden OR wellbeing OR stress OR coping) ) OR AB ( (Carer OR caregiver) N5 (burden OR wellbeing OR stress OR coping) )

S5 DE "Caregiver Burden"

S4 TI ( Parkinson* N2 dementia) OR PDD OR korsako* OR binswanger* OR huntington* OR creutzfeldt OR jcd OR cjd) OR (pick* N2 disease) OR "organic brain disease" OR "organic brain syndrome" OR (lewy* N2 bod*) OR alzheimer* OR dement* ) OR AB ( Parkinson* N2 dementia) OR PDD OR korsako* OR binswanger* OR huntington* OR creutzfeldt OR jcd OR cjd) OR (pick* N2 disease) OR "organic brain disease" OR "organic brain syndrome" OR (lewy* N2 bod*) OR alzheimer* OR dement* )

S3 DE "Alzheimer's Disease"

S2 DE "Wernicke's Syndrome"

S1 DE "Dementia"

***Cochrane CENTRAL***

#1 MeSH descriptor: [Dementia] this term only

#2 MeSH descriptor: [Wernicke Encephalopathy] this term only

#3 MeSH descriptor: [Alzheimer Disease] this term only

#4 ((Parkinson* NEAR/2 dementia) OR PDD OR korsako* OR binswanger* OR huntington* OR creutzfeldt OR jcd OR cjd OR (pick* NEAR/2 disease) OR "organic brain disease" OR "organic brain syndrome" OR (lewy* NEAR/2 bod*) OR alzheimer* OR dement*):ti OR ((Parkinson* NEAR/2 dementia) OR PDD OR korsako* OR binswanger* OR huntington* OR creutzfeldt OR jcd OR cjd OR (pick* NEAR/2 disease) OR "organic brain disease" OR "organic brain syndrome" OR (lewy* NEAR/2 bod*) OR alzheimer* OR dement*):ab

#5 #1 OR #2 OR #3 OR #4

#6 MeSH descriptor: [Caregivers] this term only

#7 (carer OR caregiver OR "care assistant" OR aide OR Supporter):ti OR (carer OR caregiver OR "care assistant" OR aide OR Supporter):ab

#8 #6 OR #7

#9 MeSH descriptor: [Guideline Adherence] this term only

#10 ((research OR Intervention* OR treatment* OR program* OR evidence) NEAR/5 (reach OR adopt* OR uptake OR fidelity OR implement* OR maint* OR (Continu* NEAR/2 us*) OR translat* OR appl* OR adapt*)):ti OR ((research OR Intervention* OR treatment* OR program* OR evidence) NEAR/5 (reach OR adopt* OR uptake OR fidelity OR implement* OR maint* OR (Continu* NEAR/2 us*) OR translat* OR appl* OR adapt*)):ab

#11 (barrier* NEAR/2 (facilitator* OR enabler*)):ti OR (barrier* NEAR/2 (facilitator* OR enabler*)):ab

#12 (Strength* NEAR/2 weakness*):ti OR (Strength* NEAR/2 weakness*):ab

#13 ((staff OR carer OR caregiver) NEAR/5 (opinion OR satisfaction)):ti OR ((staff OR carer OR caregiver) NEAR/5 (opinion OR satisfaction)):ab

#14 (Cost NEAR/2 effectiveness):ti OR (Cost NEAR/2 effectiveness):ab

#15 (RE-AIM NEAR/2 framework OR model OR dimension* OR evaluat*):ti OR (RE-AIM NEAR/2 framework OR model OR dimension* OR evaluat*):ab

#16 #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15

#17 MeSH descriptor: [Caregiver Burden] this term only

#18 ((Carer OR caregiver) NEAR/5 (burden OR wellbeing OR stress OR coping)):ti OR ((Carer OR caregiver) NEAR/5 (burden OR wellbeing OR stress OR coping)):ab

#19 (Subjective NEAR/2 burden):ti OR (Subjective NEAR/2 burden):ab

#20 ("Zarit Burden"):ti OR ("Zarit Burden"):ab

#21 (Sense NEAR/2 competence):ti OR (Sense NEAR/2 competence):ab

#22 (Affect* NEAR/2 symptom*):ti OR (Affect* NEAR/2 symptom*):ab

#23 (depress* OR anxi* OR mood):ti OR (depress* OR anxi* OR mood):ab

#24 (quality NEAR/2 life):ti OR (quality NEAR/2 life):ab

#25 #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24

#26 #5 AND #8 AND #16 AND #25

# Appendix 1.2 – Adapted StaRI Checklist

## Standards for Reporting Implementation Studies: the StaRI checklist for completion

The StaRI standard should be referenced as: Pinnock H, Barwick M, Carpenter C, Eldridge S, Grandes G, Griffiths CJ, Rycroft-Malone J, Meissner P, Murray E, Patel A, Sheikh A, Taylor SJC for the StaRI Group. Standards for Reporting Implementation Studies (StaRI) statement. *BMJ* 2017;356:i6795

The detailed Explanation and Elaboration document, which provides the rationale and exemplar text for all these items is: Pinnock H, Barwick M, Carpenter C, Eldridge S, Grandes G, Griffiths C, Rycroft-Malone J, Meissner P, Murray E, Patel A, Sheikh A, Taylor S, for the StaRI group. Standards for Reporting Implementation Studies (StaRI). Explanation and Elaboration document. *BMJ Open* 2017 2017;7:e013318

Notes: A key concept of the StaRI standards is the dual strands of describing, on the one hand, the implementation strategy and, on the other, the clinical, healthcare, or public health intervention that is being implemented. These strands are represented as two columns in the checklist.

| | |
|---|---|
| The primary focus of implementation science is the implementation strategy (column 1) and the expectation is that this will always be completed. | The evidence about the impact of the intervention on the targeted population should always be considered (column 2) and either health outcomes reported or robust evidence cited to support a known beneficial effect of the intervention on the health of individuals or populations. |

The StaRI standards refers to the broad range of study designs employed in implementation science. Authors should refer to other reporting standards for advice on reporting specific methodological features. Conversely, whilst all items are worthy of consideration, not all items will be applicable to, or feasible within every study.

<table>
<tr><th colspan="2">Checklist item</th><th>Reported on page #</th><th>Implementation Strategy</th><th>Reported on page #</th><th>Intervention</th></tr>
<tr><td colspan="2"></td><td></td><td>“Implementation strategy” refers to how the intervention was implemented</td><td></td><td>“Intervention” refers to the healthcare or public health intervention that is being implemented.</td></tr>
<tr><td colspan="6"><b>Title and abstract</b></td></tr>
<tr><td>Title</td><td><b>1</b></td><td></td><td colspan="3">Identification as an implementation study or process evaluation, and description of the methodology in the title and/or keywords</td></tr>
<tr><td>Abstract</td><td><b>2</b></td><td></td><td colspan="3">Identification as an implementation study or process evaluation, including a description of the implementation strategy to be tested or process evaluation methods used, the evidence-based intervention being implemented, and defining the key implementation/evaluation and health outcomes.</td></tr>
<tr><td colspan="6"><b>Introduction</b></td></tr>
<tr><td>Introduction</td><td><b>3</b></td><td></td><td colspan="3">Description of the problem, challenge or deficiency in healthcare or public health that the intervention being implemented aims to address.</td></tr>
<tr><td>Rationale</td><td><b>4</b></td><td>X</td><td>The scientific background and rationale for the implementation strategy (including any underpinning</td><td></td><td>The scientific background and rationale for the intervention being implemented (including evidence</td></tr>
</table>

|  |  |  |  |  |  |
|---|---|---|---|---|---|
|  |  |  | theory/framework/model, how it is expected to achieve its effects and any pilot work). |  | about its effectiveness and how it is expected to achieve its effects). |
| Aims and objectives | **5** |  | The aims of the study, (differentiating between implementation objectives and any intervention objectives). |  |  |
| **Methods: description** |  |  |  |  |  |
| Design | **6** |  | The design and key features of the evaluation, (cross referencing to any appropriate methodology reporting standards) and any changes to study protocol, with reasons |  |  |
| Context | **7** |  | The context in which the intervention was implemented. (Consider social, economic, policy, healthcare, organisational barriers and facilitators that might influence implementation elsewhere). |  |  |
| Targeted 'sites' | **8** |  | The characteristics of the targeted 'site(s)' (e.g locations/personnel/resources etc.) for implementation and any eligibility criteria. |  | The population targeted by the intervention and any eligibility criteria. |
| Description | **9** |  | A description of the process evaluation methods |  | A description of the intervention and any comparator condition |
| Sub-groups | **10** |  | Any sub-groups recruited for additional research tasks, and/or nested studies are described |  |  |
| **Methods: evaluation** |  |  |  |  |  |
| Outcomes | **11** | X | Defined pre-specified primary and other outcome(s) of the implementation strategy, and how they were assessed. Document any pre-determined targets |  | Defined pre-specified primary and other outcome(s) of the intervention (if assessed), and how they were assessed. Document any pre-determined targets |
| Process evaluation | **12** |  | Process evaluation objectives and outcomes related to the mechanism by which the intervention is expected to work |  |  |
| Economic evaluation | **13** | X | Methods for resource use, costs, economic outcomes and analysis for the implementation strategy | X | Methods for resource use, costs, economic outcomes and analysis for the intervention |
| Sample size | **14** |  | Rationale for sample sizes (including sample size calculations, budgetary constraints, practical considerations, data saturation, as appropriate) |  |  |
| Analysis | **15** |  | Methods of analysis (with reasons for that choice) |  |  |
| Sub-group analyses | **16** |  | Any a priori sub-group analyses (e.g. between different sites in a multicentre study, different clinical or demographic populations), and sub-groups recruited to specific nested research tasks |  |  |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| **Results** |  |  |  |  |  |
| Characteristics | **17** |  | Proportion recruited and characteristics of the delivering population |  | Proportion recruited and characteristics (if appropriate) of the recipient population for the intervention |
| Outcomes | **18** | X | Primary and other outcome(s) of the implementation strategy |  | Primary and other outcome(s) of the Intervention (if assessed) |
| Process outcomes | **19** |  | Process data (related to the implementation strategy mapped to the mechanism by which the strategy is expected to work) |  |  |
| Economic evaluation | **20** | X | Resource use, costs, economic outcomes and analysis for the implementation strategy | X | Resource use, costs, economic outcomes and analysis for the intervention |
| Sub-group analyses | **21** |  | Representativeness and outcomes of subgroups including those recruited to specific research tasks |  |  |
| Fidelity/ adaptation | **22** | X | Fidelity to implementation strategy as planned and adaptation to suit context and preferences | X | Fidelity to delivering the core components of intervention (where measured) * |
| Contextual changes | **23** |  | Contextual changes (if any) which may have affected outcomes |  |  |
| Harms | **24** |  | All important harms or unintended effects in each group |  |  |
| **Discussion** |  |  |  |  |  |
| Structured discussion | **25** |  | Summary of findings, strengths and limitations, comparisons with other studies, conclusions and implications |  |  |
| Implications | **26** |  | Discussion of policy, practice and/or research implications of process evaluation findings |  | Discussion of policy, practice and/or research implications of the intervention (specifically including sustainability) |
| **General** |  |  |  |  |  |
| Statements | **27** |  | Include statement(s) on regulatory approvals (including, as appropriate, ethical approval, confidential use of routine data, governance approval), trial/study registration (availability of protocol), funding and conflicts of interest |  |  |

## Appendix 1.3 – Sample of Deductive Coding of Implementation Information

| Reference | Data gathered from papers | Codes |
|---|---|---|
| Cheu et al (2009) | “Analysis of the follow-up interviews showed that caregivers varied in the ways they felt about using technology to access services and in the degree to which an online service was beneficial…” (p.329)<br>“*Needing Help to Access Accounts in an Unfamiliar Portal.* Most participants had used e-mail and had a regular e-mail account for personal use. When using an e-mail account in a Web-based portal, some were able to access the account and solve technical problems. For example, one caregiver said, “I haven’t used it. I can’t find the address.” Others relied on their spouse or children to help solve related problems (e.g., going to the portal’s URL address, logging onto the e-mail account, and/or typing and sending e-mails). Because caregivers did not access the accounts frequently, they often forgot their user name and password or forgot that they had access to a support service. A caregiver said, “I sometimes forgot to check the e-mails and the e-mails piled up.” “ (pp. 331-332) | Barrier – accessing unfamiliar online platform. |
| Easom et al., (2013) | “A total of twelve contacts, by the interventionist, with each caregiver were desired, but the type of contact could vary. Specifically, a caregiver could substitute four of the in-home visits for telephone visits. This adaptation differed from the original REACH II intervention which allowed up to two by phone visits that could be substituted for home visits.” (p. 74) | Adaptation - Increased flexibility in mode of contacts (home visit versus telephone) |

| | | |
|---|---|---|
| | “We considered geographical distances when planning the recruitment process. An outreach plan was created by the investigators and recruitment was continuous over a three-year period. Flyers and brochures were developed and delivered to aging agencies, faith-based agencies, the medical community, emergency responders, stores, and markets in the rural counties. Oral presentations were given at churches, civic group meetings, and health care fairs to advertise the program.” (p.72) | Adaptation – increased recruitment efforts for rural intervention. |
| | “Accountability for enrollment was expanded to all team members. Marketing and recruitment activities held priority in weekly meetings and interventionists were also utilized to promote the program when not engaged in direct service delivery. Interestingly, outreach to social service providers, specifically senior and community centers yielded the greatest return and resulted in an increase in program enrollment. Marketing to local retail businesses, posting flyers and leaving brochures, was probably the most ineffective recruitment strategy for the number of participants recruited.” (p.83) | Effective adaptation – outreach to social service providers to increase reach.<br>Likely ineffective adaptation – marketing for recruitment. |
| Hinton et al. (2020) | “Changes to content included numerous modifications of the intervention manual and caregiver notebook to make the scripts, examples, and resources appropriate to the culture and literacy level of the target population (e.g., substituting culturally relevant examples, simplifying language), and expanding the amount of time in across intervention sessions devoted to caregiver education about AD. Changes to context/delivery included participation of multiple family members in the | Adaptation – altering content of information to suit culture and literacy levels. |

| | | |
|---|---|---|
| | intervention when appropriate, engaging the male head of the household in the initial session to facilitate participation and retention, and in most cases conducting weekly rather than biweekly sessions to sustain momentum. Changes to training included supplementing standard REACH VA training with principles of Buddhism to enhance interventionist skills and conducting a small case-series to give interventionists hands-on experience." (pp. 3-4) | Adaptation – increased time on psychoeducation.<br>Adaptation – involving more family members.<br>Adaptation – more frequent sessions (weekly versus biweekly)<br>Adaptation – enhanced training for interventionists |

## Appendix 1.4 – Sample of Grouping and Rating of Implementation Information Codes

| Title | Adaptations | Added recruitment strategies | Changes to ratio of mode of contact | Changes to frequency, number, or length of intervention | Changes to content of intervention or materials to suit context | Added/ removed components of intervention content | Changes to targeted receiving population | Additional support for interventionist population | Additional support for receiving population | Barriers | Accessing online interventions |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Internet-based caregiver support for Chinese Canadians taking care of a family member with Alzheimer disease and related dementia | | | | | | | | | | | Y |
| A Rural Community Translation of a Dementia Caregiving Intervention | | Y | Y | | | | | | | | |
| Advancing family dementia caregiver interventions in low- and middle-income countries: A pilot cluster randomized controlled trial of Resources for Advancing Alzheimer's Caregiver Health in Vietnam (REACH VN) | | | | Y | Y | Y | Y | Y | | | |

## Appendix 2.1 – Approved MRP proposal

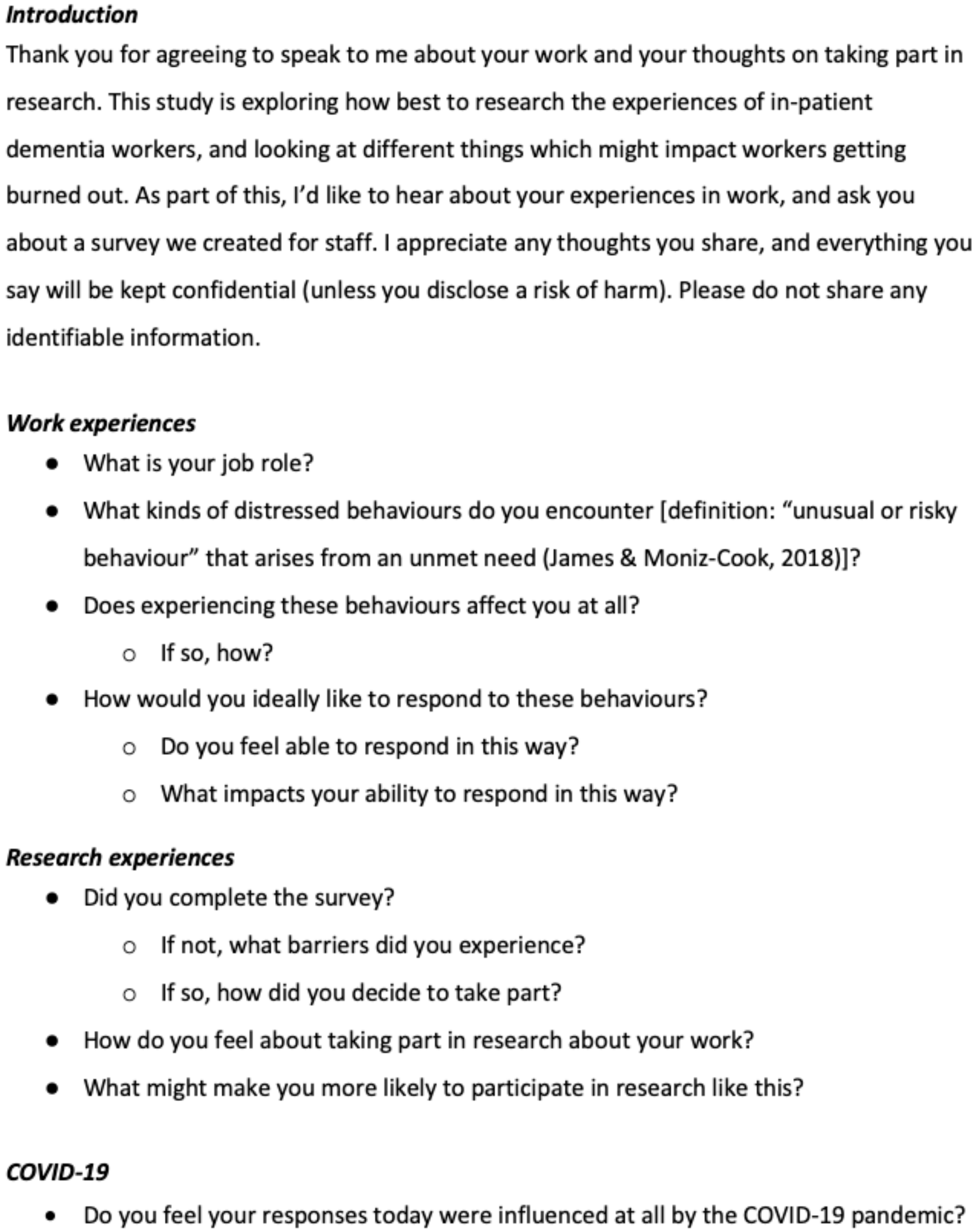
Proposal can be viewed at the following link:
https://osf.io/acweu/?view_only=e08728d11de9409aa94743ac024f216e.

## Appendix 2.3 – Participant Information Sheet, Privacy Notice, Consent Forms and Survey

Documents can be viewed at:

https://osf.io/acweu/?view_only=e08728d11de9409aa94743ac024f216e .

## Appendix 2.4 – Interview Schedule



### *Introduction*

Thank you for agreeing to speak to me about your work and your thoughts on taking part in research. This study is exploring how best to research the experiences of in-patient dementia workers, and looking at different things which might impact workers getting burned out. As part of this, I'd like to hear about your experiences in work, and ask you about a survey we created for staff. I appreciate any thoughts you share, and everything you say will be kept confidential (unless you disclose a risk of harm). Please do not share any identifiable information.

### *Work experiences*

- What is your job role?
- What kinds of distressed behaviours do you encounter [definition: "unusual or risky behaviour" that arises from an unmet need (James & Moniz-Cook, 2018)]?
- Does experiencing these behaviours affect you at all?
  - If so, how?
- How would you ideally like to respond to these behaviours?
  - Do you feel able to respond in this way?
  - What impacts your ability to respond in this way?

### *Research experiences*

- Did you complete the survey?
  - If not, what barriers did you experience?
  - If so, how did you decide to take part?
- How do you feel about taking part in research about your work?
- What might make you more likely to participate in research like this?

### *COVID-19*

- Do you feel your responses today were influenced at all by the COVID-19 pandemic?

***Closing***

Thank you again for agreeing to speak to me about your thoughts and experiences. I very much appreciate you taking this time to share this information with me. If you find that participating in this conversation has raised any difficult feelings that you struggle to cope with, please contact the resources outlined in the information sheet.

James, I. A., & Moniz-Cook, E. (2018). *Evidence Briefing: Behaviour that challenges in dementia*. Retrieved from https://hull-repository.worktribe.com/output/915932/evidence-briefing-behaviour-that-challenges-in-dementia

## Appendix 2.5 – Examples of Thematic Analysis Process

### *Excerpt of Reflective Notes*

**From Transcription and Familiarisation - Interview 2.**

- ‘really affected us in the beginning’ – inexperience compounding impact of experiencing DBs. What is it about experience that changes nurses’ emotional and behavioural responses? Are they able to be more distanced?
- Empathy meaning that they can’t show their own responses. Attuning and soothing, to bring down distress and restore safety
- Not noticing own responses in the moment
- I am impressed by the staff’s ability to stay calm in the face of sometimes dangerous behaviours
- Less about empathy directly relating to burnout, and more about it providing a helpful route to responding to DBs
- Practical ability to respond hampered by high level of needs, number of patients, lack of staff.
- Desire to take part in research to be ‘heard’ – this resonates with me
- Recruiting psychologist well-known to staff – facilitated research participation?

**Coding - Interview 2.**

- Describing experiencing lots of the same DBs at the same time – I can’t help but empathise with this and recall my experiences as a support worker – the sense of overwhelm when surrounded by difficult to manage (and potentially unsafe) behaviours, that are self-perpetuating
- Despite some possible difficulty for participant identifying own responses, I see myself digging into this more – seeking their labelling of the impact of these DBs on their own coping etc
- I notice myself applying psychological understanding to descriptions of the impact of DBs e.g., fight/flight/freeze to stress. Could also formulate as red zone of window of tolerance.
- Idea: Could I invoke the window of tolerance on individual and team level in interpretation of data?

- How does lack of awareness of own responses impact staff? Could lead to them pushing through and possibly pushing self too far? Could this unconsciously impact how they relate with patients (compassion fatigue, as named by one participant)?
- Noticing me dropping in ‘empathy’ as a term again.

## *Excerpt of Coded Transcript*

Transcription key:

[XX] = Identifiable information omitted

(-) = Shorter than a pause

(...) = Pause

CAPITAL LETTERS = Emphasis

Brackets ( ) = Contains additional interview information

P1 etc = Participant

I = Interviewer

I: Okay. Em, and does experiencing these behaviours AFFECT you at all?

P2: I think, it did, especially when I started with, em, older adult, I think because I didn't have the EXPERIENCE of it. Eh, I felt like it really affected us in the BEGINNING. Em, and I think (-) it's hard, I think, it does probably more than I recognise, that it does, if that makes any kind of sense, em (-) But I think definitely, when there's a lot of kinda patients, in at the same time, with the same distressed behaviours-

I: Mhm

P2: -I think that can be quite, DAUNTING, I think, especially if we've not got any staff on or we're short-staffed, cos you're tryna obviously do what's best for the patient and, if everybody at the same time has the same behaviour it's quite, that can be quite distressing for us, as well (overlapping)

I: Yeah, yeah

P2: - but we just need to try and manage that as best as we can, I suppose.

I: Mmm. Yeah. And so is there anything in particular that, in terms of how it affects you when you're experiencing that, is there anything in particular that you've noticed, in terms of that effect on YOU?

P2: Em (…) I don't know really, when I'm (…) I think more when you're kinda (…) you become more, well I can only speak for myself, personally, but I feel like I become more (…) stressed, and more, kinda (-) I don't want to say ON EDGE, because you're not really being ON EDGE, but you're more (-) AWARE, and you're more SENSITIVE to what's going on, what's happening, and (-) I think you just, (quiet) I don't know (louder) I don't know how to explain what I mean, but em (-) suppose it can just affect everybody in different ways, and I feel I don't realise until I go HOME, how it's affected me until I'm kinda SPEAKING about it. Even now, when I'm trying to think, I'm like, I don't because, when I'm on the ward, it just, (quieter) I don't know. (louder) I think there's just so many ways I am un- unaware of.

I: Mhm, yeah. It sounded like there's something there about you may be becoming a bit kind of HEIGHTENED in those moments?

P2: Yes.

I: You said, not on edge, but something like that.

P2: Yes, just trying to be, aware of everything that's going on, round about you, but also focusing on patients that are more DISTRESSED at that time-

**Commented [HM(1]:** Impact of DBs worse with less experience

**Commented [HM(2]:** Impact of DBs – 'probably more than I recognise'

**Commented [HM(3]:** Impact of DBs – daunting when lots of same DB at same time

**Commented [HM(4]:** Impact of DBs, especially if short-staffed

**Commented [HM(5]:** Impact of DBs – distressing when lots of same DBs at same time

**Commented [HM(6]:** Ideal response – have to do best for patient, while stressed

**Commented [HM(7]:** Impact of DBs – possible difficulty naming

**Commented [HM(8]:** Impact of DBs - stress

**Commented [HM(9]:** Impact of DBs – possible fight, flight, freeze repsonse

**Commented [HM(10]:** Impact of DBs – increased awareness, sensitivity

**Commented [HM(11]:** Impact of DBs – possible difficulty naming

**Commented [HM(12]:** Impact of DBs – different for each person

**Commented [HM(13]:** Impact of DBs not noticed until home

**Commented [HM(14]:** Impact of DBs – possibly unaware of all impacts

**Commented [HM(15]:** Impact of DBs – increased awareness, sensitivity

I: Mhm

P2: -and I think that can be quite DIFFICULT. Em, and you kinda have to rely on colleagues as well, and if they're feeling stressed by the situation, em, like sometimes, it can have a bit of a knock on effect I think. It's just it's (-) I don't want to use words that are gonna make it sounds really bad, but -

I: Safe space (laughs)

P2: I know I just, I know like sometimes (-) I think STRESSED is probably the best way to describe how it affects me.

I: That makes sense. Yeah.

**Commented [HM(16]:** Response to DBs – aware of everything while focussed on distressed patient

**Commented [HM(17]:** Response to DBs – having to reply on stressed colleagues

**Commented [HM(18]:** Impact of DBs - stress

*Thematic Analysis Initial Theme Development Mind Map*