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Understanding the impact of apathy in people with dementia on formal carers within residential settings

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Chapter 1: Systematic Review

Evidence-based, non-pharmacological interventions for apathy in dementia within residential care settings: a systematic review of the literature using the RE-AIM framework

Emma Neilson, Hannah M. Miller & Hamish J. McLeod

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Word limit = 350 for abstract and 12,000 for main text (excluding tables, figures, and references)

1.1 Abstract

Background Apathy is a highly prevalent distressed behaviour (DB) in people with dementia (PWD) living in residential care settings. Non-pharmacological interventions are the recommended first-line treatment for DB and although many have been evidenced to be effective for apathy, studies assessing the translation of their efficacy into practice are rare.

Objectives: We used a modified form of the RE-AIM process evaluation framework to describe and evaluate the strategies used to facilitate implementation of these interventions for apathy in residential care and describe how these may inform future intervention planning.

Methods A systematic review of the literature was conducted using five databases (MEDLINE, Embase, PsycInfo, CINAHL, Cochrane Library – CENTRAL) and hand-searching of reference lists. Studies were included if they used a non-pharmacological intervention previously reported to be effective for apathy in PWD, used samples of PWD living in residential care settings, reported effectiveness for a measure of (or including) apathy, and provided information on effectiveness (plus one other domain) in the RE-AIM (Reach, Effectiveness, Adoption, Implementation, Maintenance) framework. Articles were critically appraised using the Mixed Methods Appraisal Tool (MMAT) and analysed using a narrative synthesis.

Results Thirteen studies met inclusion criteria including 850 PWD (average *n* = 65 per study, ~33 per group) from 29 care homes (Mean= 84 years; range= 58-101 years). Interventions included: music (*n* = 6), multi-sensory stimulation (*n* = 3), pet-robot therapy (*n* = 2), reminiscence group therapy (*n* =1), and therapeutic conversation (*n* = 1). Limited use of apathy outcomes, lack of manualised protocols for non-pharmacological interventions in the literature base as well as limited reporting of reach, adoption and implementation domains in eligible studies made identifying effective components of interventions difficult.

Discussion Several strategies that may facilitate future implementation planning for apathy interventions within residential care were identified. These included consideration of the target population needs; careful selection of intervention types; development, accurate reporting of and adherence to apathy-specific interventions; adaptations in relation to population need (e.g., dementia/apathy severity and ill-health); clear reporting of adaptations; thorough evaluation of staff attitudes, resource, and support for implementing interventions; organisational resource; and evaluation of long-term intervention effects.

1.2 Introduction

Recent reports suggest that there are around 55-million worldwide cases of dementia and that around 10-million new cases are identified every year (www.who.int/news-room/fact-sheets/detail/dementia). Without advancements in the provision of effective interventions, dementia-associated costs of care are anticipated to rise due to increased needs for care home admission (e.g., Wittenberg et al., 2020). Distressed behaviours (DB; James et al., 2011; also commonly referred to as Behavioural and Psychological Symptoms of Dementia (BPSD) in the literature), including agitation and apathy, are highly prevalent in people with dementia (PWD) living in residential care (Cerejeira et al., 2012, Rajkumar et al., 2016) and are linked to high caregiver burden (Isik et al., 2019).

Apathy is consistently categorised as a BPSD/DB but has some similarities and differences with other DB's. Firstly, unlike other DBs, apathy is a complex syndrome that has, historically, been difficult to define (Massimo et al., 2018). However, current definitions describe it as "the quantitative reduction of self-generated voluntary and purposeful behaviours" (Levy & Dubois, 2006; Massimo et al., 2018). Apathy can therefore occur because of disruptions in one of three processes; motivation, planning, and initiation, suggesting it has cognitive, emotional, and behavioural components. Unlike other DB's, apathy can also be partly explained by neuro-anatomical and -biological dysfunction (Massimo et al., 2018; Le Heron et al., 2019). Conceptual neurobiological as well as behavioural frameworks have been proposed to develop our understanding of apathy but have been limited by the lack of consensus in the literature on what specific cognitive processes are impaired and how motivated behaviour occurs (Le Heron et al., 2019). However, Massimo et al. (2018) have recently developed a 'conceptual model of factors associated with apathy in dementia' - adapted from a previous framework for DB’s more generally (Kales et al., 2015). This model highlights that, similarly to other DB’s, a number of patient, caregiver, and environmental factors can trigger apathy in PWD and provides a framework to support development and assessments of effectiveness of interventions for apathy in dementia (Massimo et al., 2018).

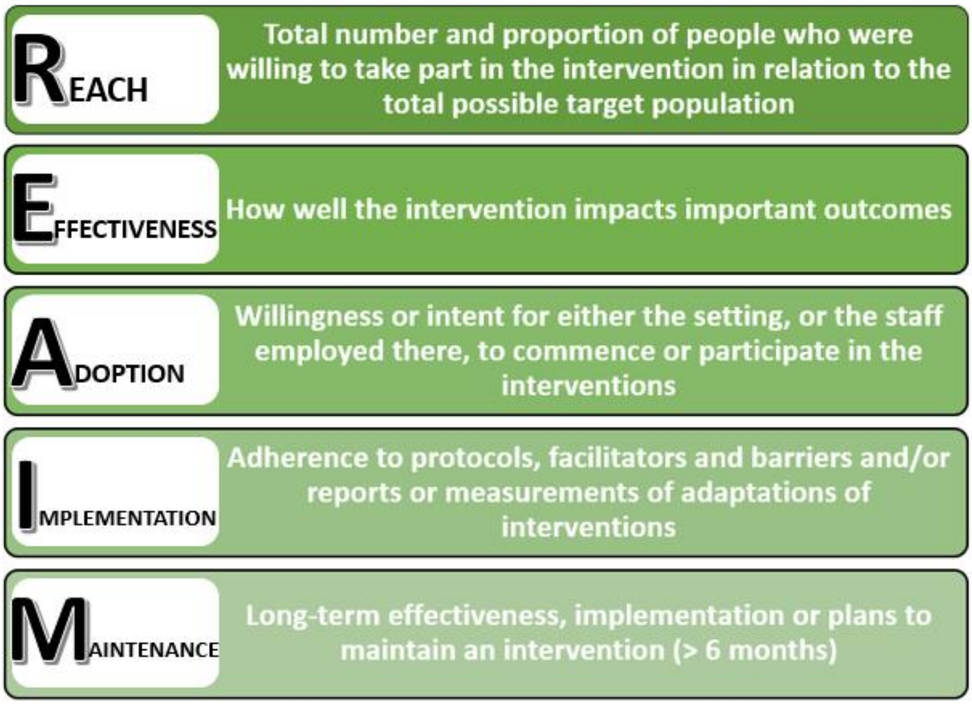
Based on our current understanding, apathy has been found to be among the most prevalent of DB, a source of distress for both formal and informal carers and linked with a poor prognosis (Rajkumar et al., 2016) as well as potentially higher risk of neglect (Mast et al., 2022). Despite this, apathy is often not accurately assessed or measured (Burgon et al., 2021) and is not generally well researched (Dening et al., 2021), possibly due to the aforementioned difficulties in defining it. However, the current evidence-base suggests that symptoms of apathy can respond well to intervention (Dening et al., 2021) and a recent dementia research advancement strategy has highlighted treatment and prevention of apathy in dementia as a priority (Pickett et al., 2018).

Drug treatments, such as antipsychotics, were previously the mainstay of interventions for DB. However, these mainly targeted more ‘active’ symptoms of dementia, such as agitation (Mühlbauer et al., 2021). Furthermore, pharmacological interventions have been evidenced to be either ineffective or, at times, adverse for apathy (Bogdan et al., 2019), with a number of adverse effects also reported for agitation (Mühlbauer et al., 2021). Numerous treatment guidelines published since 2008 (Ngo & Holroyd-Leduc, 2015) recommend non-pharmacological interventions as the first-line approach for supporting PWD with any DB.

Various non-pharmacological interventions have now been evidenced as suitable for people with dementia (e.g., MATRIX, 2014, in Scotland) with studies assessing their effectiveness for both DB generally (Scales et al., 2018) as well as apathy specifically

(Theleritis et al., 2018, Brodaty & Burns, 2012). However, these reviews demonstrate that the evidence of efficacy for these interventions to symptoms of apathy is varied (Theleritis et al., 2018, Brodaty & Burns, 2012). An umbrella review suggested the interventions with the most robust evidence of effectiveness for apathy were; music, multi-sensory stimulation, cognitive stimulation and animal/pet-assisted (including social robots) therapies (Cai et al., 2020). Other interventions such as reminiscence therapy, therapeutic conversation and art therapy were also noted as promising but had less conclusive evidence (Cai et al., 2020). However, there is much less research assessing how such interventions can be successfully implemented in “real-world” settings, such as care homes, over extended periods of time (Boersma et al., 2015).

Translating interventions with proven efficacy from research trials, into daily practice within care home settings has been a long-standing difficulty (Gitlin et al., 2015). Suggested reasons for these difficulties can be at the organisational level (e.g., lack of funds and resources to implement and sustain interventions, top-down managerial structures that hamper communications) and/or the staff level factors (e.g., lack of staff buy-in, staff turnover and job demands; Gitlin et al., 2015, Pimentel et al., 2020, Surr et al., 2019). Due to the complexity of this environment, the specific reasons for an intervention failing to be implemented or work as described are not always clear (Boersma et al., 2015). Process evaluations, which assesses the quality of the implementation of an intervention as well as determining the mechanisms by which it can be effective, have been proposed as a method to support this understanding (Moore et al., 2015) and to facilitate ways in which we can make interventions work in real-life. The RE-AIM (Reach, Effectiveness, Adoption, Implementation, Maintenance) framework is an example of a process evaluation framework that can be used to plan and/or evaluate interventions for this purpose (Glasgow et al., 2019). The RE-AIM framework comprises of 5 dimensions: Reach, Effectiveness, Adoption, Implementation, and Maintenance, as described in **Fig. 1.1**.



REACH	Total number and proportion of people who were willing to take part in the intervention in relation to the total possible target population
EFFECTIVENESS	How well the intervention impacts important outcomes
ADOPTION	Willingness or intent for either the setting, or the staff employed there, to commence or participate in the interventions
IMPLEMENTATION	Adherence to protocols, facilitators and barriers and/or reports or measurements of adaptations of interventions
MAINTENANCE	Long-term effectiveness, implementation or plans to maintain an intervention (> 6 months)

Fig. 1.1: Infographic describing the dimensions of the RE-AIM framework as operationalised within the current review. Content adapted from (Glasgow et al., 2019, Boersma et al., 2015)

This framework was used as it allows for a) an evaluation of strengths and weaknesses of a studies reporting and b) consideration of a range of dimensions necessary for successful implementation, which can be rated at the organisational and individual level (Boersma et al., 2015).

1.2.1 Aims

The aims of the current study were to describe and evaluate the implementation strategies used for effective non-pharmacological interventions for treating apathy in PWD within residential care settings. By focusing on studies that included process evaluation information and assessing them within the dimensions of the RE-AIM framework (Glasgow et al., 2019) we addressed the following key questions:

In studies which a) used non-pharmacological interventions known to be effective for apathy and b) involved PWD within residential care settings,

1) What strategies have been used in research to facilitate their implementation?
2) How effective are these strategies for facilitating implementation according to the RE-AIM process evaluation framework?
3) How could this information inform future implementation planning for these interventions?

1.3 Methods

We systematically reviewed process evaluation studies meeting the eligibility criteria below. The protocol we designed and used for this study was not published on prospero but has been uploaded to the Open Science Framework (OSF) website (OSF_SRProtocol). The study was conducted and reported in line with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009).

1.3.1 Eligibility Criteria

Included studies had to meet the following eligibility criteria:

1. Published in English in peer-reviewed journals.
2. The people receiving the interventions had to be PWD and not another condition.
3. Interventions were required to be non-pharmacological and evidenced to be effective in the treatment of apathy in dementia as reported in (Cai et al., 2020). Accepted intervention types included were: music, cognitive stimulation therapy, animal-assisted therapy, multi-sensory stimulation therapy, reminiscence therapy, therapeutic conversation, progressive muscle relaxation, art therapy, exercise therapy, and occupational therapy.

4. The study had to provide evidence that the tested intervention was effective in alleviating apathy. Apathy could be assessed by either a specific measure or via a measure in which apathy is included or can be inferred.
5. Interventions had to be implemented within long-term residential care settings and report descriptions of the implementation practices that could be assessed within the RE-AIM framework (Glasgow et al., 2019). To be assessed within the RE-AIM framework, studies had to demonstrate effectiveness (in relation to an apathy outcome) plus meet criteria for one other dimension.
6. Interventions were required to be implemented by either care staff or professionals/professionals in training who were trained to deliver the therapy/approach, and be implemented in or after 2008 (when dementia guidelines world-wide advised non-pharmacological interventions to be the first line treatment for DB; Ngo & Holroyd-Leduc, 2015).

RCTs, non-randomised intervention studies (NRIS) and qualitative studies were accepted due to the focus of the review being on implementation processes as opposed to purely quantitative effects.

Studies were excluded if: the interventions used were pharmacological or included prescribing medication; were implemented in the community, homecare, in-patient or ward settings; were for people without dementia (e.g., older adults in general); or if only information relating to the effectiveness dimension of the RE-AIM framework was reported.

1.3.2 Search Strategy

Five databases, on three different platforms, were searched on 01/06/22: MEDLINE (EBSCOhost; 1946 to present), Embase (Ovid; 1947 to present), PsycInfo (EBSCOhost;

1967 to present), CINAHL (EBSCOhost; 1980 to present), Cochrane Library – CENTRAL.

The search strategy was adapted from previous relevant studies (Bennett et al., 2021, Boersma et al., 2015) and included terms for “process evaluation”, “dementia”, “BPSD”, and residential care setting. “BPSD” as opposed to “apathy” itself was used as a search term as it was considered the most inclusive way to access literature assessing apathy. This was considered necessary for several reasons; apathy as a construct has less reliable specific measures within the literature than other DB (Burgon et al., 2021), behavioural symptoms are often assessed using measures for multiple DB (e.g., NPI), and there is a paucity of research that assesses the effectiveness of interventions explicitly for apathy (Cai et al., 2020). Due to the range of possible interventions and the names that are used for them, the search was not restricted by intervention type (in line with Boersma et al., 2015). This strategy was adapted for implementation on all five databases, copies of the strategies for each database can be found in **Appendix A1.** The reference lists of all included articles were also checked for any further relevant articles and this search resulted in an additional five articles for inclusion. On review of abstracts these articles seemed to have been missed by the initial search due to the abstracts not containing any of the search-terms related to implementation/process evaluation which were adapted from Bennett et al. (2021). Consideration of adaptations to the strategies that may have allowed for identification of these articles are reviewed in **Appendix A1**.

1.3.3 Selection Process

With the support of a specially designed screening tool (OSF_ScreeningTool), researcher EN, screened all titles and abstracts for inclusion. HMM reviewed a subset of these (*n*=55) independently resulting in an agreement rating of 98% for eligibility judgements. The single disagreement related to whether the focus of the intervention was DB and was resolved through discussion. Full-text of articles remaining after title/abstract review were then screened by EN. HMM independently rated five of these articles for inclusion eligibility which resulted in an overall agreement of 80%. Disagreement related to criteria for 'Implementation' of RE-AIM and was resolved through discussion.

1.3.4 Data Collection Process

A data extraction tool was created by EN (see OSF_SRProtocol) to facilitate collection of study characteristics relevant for synthesis. Characteristics included in the tool were: study design, participant (PWD) characteristics, type of intervention used, characteristics of sample delivering intervention, RE-AIM framework dimensions. Relevant data from the included articles were entered into tables. Any missing or unclear information was not sought from other sources but was noted as missing within the relevant data tables/descriptions.

1.3.5 Data Synthesis

Due to the variation in study reporting/methodology styles, data were summarised using a narrative synthesis method (Popay et al., 2006). The 'RE-AIM Planning and Evaluation Framework' was used as the model to inform the review. Preliminary synthesis to identify the facilitators and barriers to implementation were conducted in a number of ways: first, presenting descriptive elements of the papers in a table (including setting, study design, overall dementia samples included, and the interventions implemented) followed by the tabulation and description of implementation/process evaluation outcomes (the main effect measures). Process evaluation outcomes were presented within the context of the 'RE-AIM Planning and Evaluation Framework' which included five dimensions for assessment (Reach, Effectiveness, Adoption, Implementation, and Maintenance; Glasgow et al., 2019). A score out of five was assigned for each paper to highlight how many of each of these domains were reported, frequencies of each of these domains across papers are also provided (see **Table 1.2**). Furthermore, implementation characteristics of interventions were described and a bar graph was used to demonstrate the available information on ‘Reach’ across studies Factors that could explain variations in the facilitators/barriers identified across studies (e.g., populations, intervention types, outcome measures used, etc.) as well as the effect sizes of the interventions were then explored. Robustness of this synthesis was assessed using quality appraisal results (tabulated in **Table 1.1**) and any reductions in ratings were reviewed in the results (**1.4.4 Quality Appraisal (QA**) and discussion (**1.5 Discussion**) with further implications of these ratings discussed in the latter section**.**

1.3.6 Quality Appraisal (QA)

Due to the variability in study designs included, quality was assessed with the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). Each type of study design has five items assessing quality that can be rated as “yes”, “no” or “can’t tell” (Hong et al., 2018). EN rated all included papers with HMM co-rating a sub-sample of five. An agreement rating of 92% was obtained, with disagreements resolved through discussion.

In line with guidance from the authors (Hong, 2022) an overall rating of quality for all eligible papers was indicated by awarding a star (*) for every item that received a “yes” rating; allowing for a possible range of ratings between 1-star and 5-stars; with a higher number of stars indicating a higher QA rating. The ratings for each paper can be found in **Table 1.1.**

1.4 Results

1.4.1 Study Selection

The above search strategies identified 4,461 articles after duplicates were removed. After title screening (by EN) 277 articles were brought forward for full-text screening ; a total of eight articles (plus one addendum) were included for data synthesis. Articles from the citation lists of all included articles (*n = 8)* as well as the nine systematic reviews included in Cai et al.’s umbrella review were also considered for eligibility; 13 were brought forward for full-text review and five of these were included in the data synthesis. **Fig. 1.2** outlines the search results and selection decisions in full.

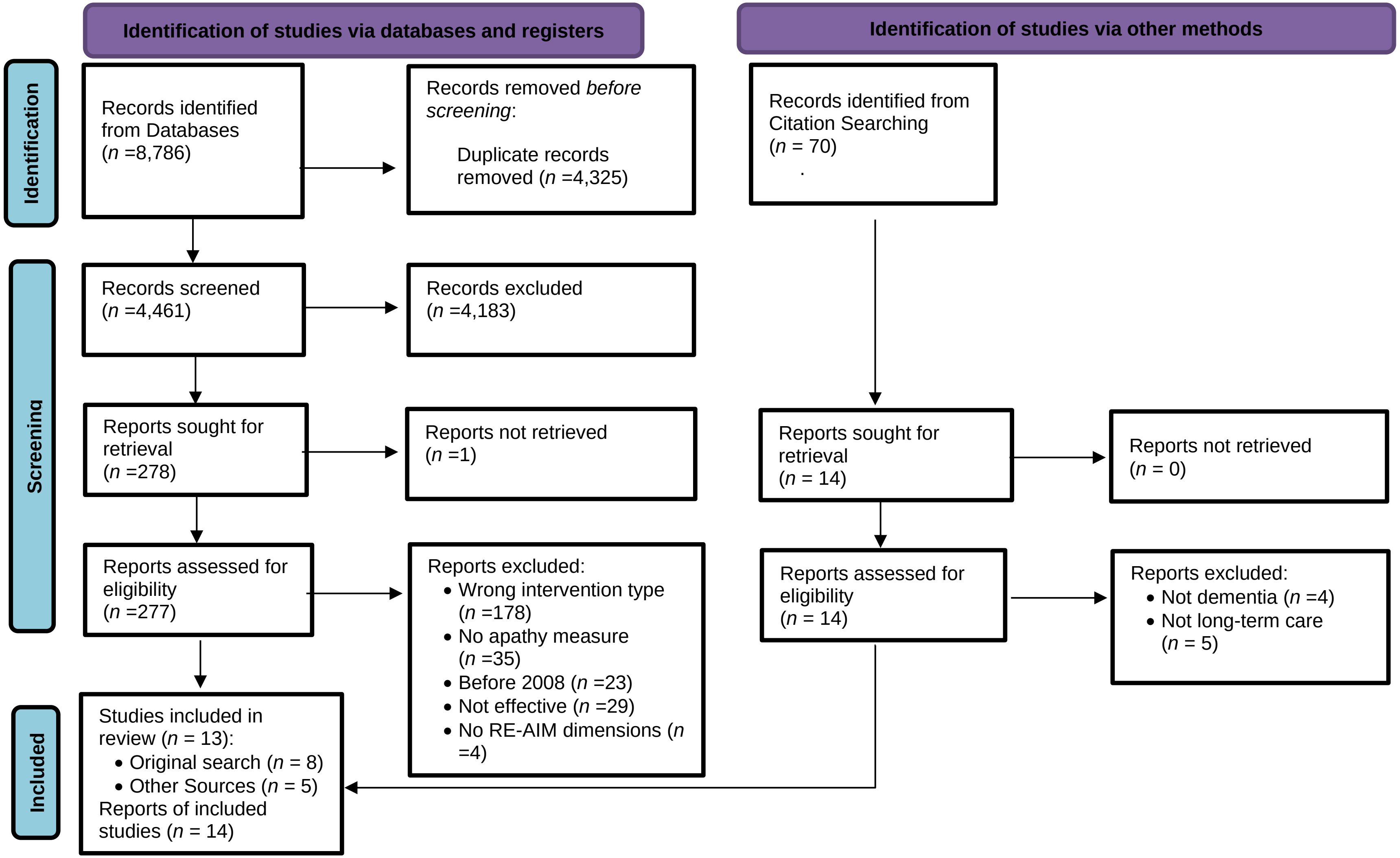


Fig 1.2: PRISMA flow diagram of search results at each stage (Page et al., 2021)

1.4.2 Study Characteristics

1.4.2.1 Setting and Design An overview of the study characteristics for all articles can be found in **Table 1.1** along with the overall QA ratings. Briefly, all 13 studies, by nature of the inclusion criteria were implemented within residential care settings. The majority of the studies were conducted in Europe (*n* = 7), with the remaining studies located in America, China, Taiwan and Australia. A range of study designs were employed but overall, 11 were quantitative (ten RCTs) and two used mixed methods. No purely qualitative studies met eligibility criteria.

1.4.2.2 Dementia samples Across all studies, 850 PWD were recruited (Mean *n* = 65 per study (~33 per group), Range *n* = 12-275). The average age of PWD was 84 years (Range = 58-101 years). Only six studies reported the types of dementia participants were diagnosed with, with Alzheimer's being most prevalent. Twelve studies reported dementia severity ratings for their sample: three completed interventions with people across the full mild-severe range of dementia, two with mild-moderate, three with moderate-severe, and four with severe dementia. Four of these studies purposely targeted specific levels of dementia severity for intervention (Raglio et al., 2010;2012, D'Aniello et al., 2021, Sánchez et al., 2016, Hsieh et al., 2010) and one specifically stratified their sample and adapted interventions based on severity ratings (Valenti Soler et al., 2015). Apathy was assessed for all studies, but a range of measures were used (see **Section 1.4.2.4**) and none provided specific severity ratings. However, higher scores are generally reflective of a higher severity of apathy and Tang et al. (2018) reported a pattern of higher apathy scores being associated with more severe dementia.

1.4.2.3 Interventions As specified in the inclusion criteria, only interventions with more robust evidence of effectiveness (larger numbers of studies with higher quality data demonstrating their effectiveness for apathy as assessed and reported in a recent umbrella review: Cai et al., 2020), were accepted for review. Eligible articles included the following interventions: music (receptive and interactive), multi-sensory stimulation environments (MSSE), animal-assisted therapy using social robots (robot-pet therapy), reminiscence therapy, and therapeutic conversation. The most reported intervention was music therapy (5/13 studies). See **Table 1.1.**

Table 1.1 Characteristics of eligible studies

				Experimental Group		Control Group				
Author (Year)	**Study Type**	**Country** (No. of care homes)	**Experimental Intervention**	***N,*** **Age** M(SD), Range	***Dementia Severity Scale*** Mean (SD), Range	***N,*** **Age** M(SD), Range	***Dementia Severity Scale*** Mean (SD), Range	**Control Intervention**	**Apathy Measure**	**QA (MMAT)**
Ragilo et al. (2010) Plus Addendum: (2012)	RCT	Italy (5)	MT	*n* = 30 85.4 (6.5) 74-99	*CDRS* *(index score 1-5)* 2.8 (0.4), 2-4 Moderate-Severe	*n* = 30 84.6 (6.8) 69-96	*CDRS* *(index score 1-5)* 2.9 (0.6), 2-4 Moderate-Severe	Standard care	NPI	***
Hsu et al. (2015)	Cluster RCT & Interviews (Mixed Methods)	UK (2)	MT	*n* = 9 84.56 (6.64) -	*GDS* 5.89 (1.05) Moderate-Severe	*N* = 8 82.50 (13.04) -	*GDS* 5.50 (1.31) Moderate-Severe	Standard care	NPI-NH	*
Murphy et al. (2018)	Quality Improvement Project	America (1)	Personalised Music Intervention	NA	NA	NA	NA	NA	Observed Behaviour	**
Tang et al. (2018)	RCT	China (1)	MT	*n* = 38 76.39 (4.86)	*MMSE* 16.42 (4.89) Mild-Moderate	*n* = 39 75.38 (4.94)	*MMSE* 15.77 (4.64) Mild-Moderate	Standard care	AES	****
D'Aniellllo et al. (2021)	RCT	Italy (1)	MT	*n* = 30 89.50 (6.96)	*MMSE* 9.45 (6.66) Moderate-Severe	*n* = 30 89.50 (6.96)	*MMSE* 9.45 (6.66) Moderate-Severe	Standard care	NPI	****
Dahms et al. (2021)	NRIS (within-subjects) Longitudinal	Germany (3)	MT and Personalised Music	*n* = 30 81.4 (9.0)	*MMSE* 8.5 (7.4)	NA	NA	6 different music interventions used	NOSGER	***
Anderson et al. (2011)	NRIS (within-subjects) & Focus Group	Australia (1)	Snoezelen	*n* = 12 89 (8.19) 81-94	*MMSE* 5.7 0-13 Severe	NA	NA	Garden Activity Sessions	Observed Behaviour	*

	(Mixed Methods)									
Maseda et al. (2014)	Controlled Longitudinal Trial - RCT	Spain (1)	MSSE	*n* = 10 87.2 (6.8) 77 - 96	*GDS* 4-7 Moderate - Severe	*n* = 10 86.7 (4.5) 79-92	*GDS* 4-7 Moderate-Severe	Standard care Third group = ‘Activity’	NPI	***
Sánchez et al. (2016)	Pilot RCT	Spain (1)	MSSE	*n* = 11 86.4 (7.9) 71-96	*GDS* 6-7 Severe	*n* = 10 82.3 (11.0) 68-102	*GDS* 6-7 Severe	Standard care Third group = ‘Activity’	NPI	***
Valenti Soler et al. (2015) Phase 1	Pilot RCT	Spain (1)	Pet Social Robot – PARO	*n* = 33 84.68 (-) 58-100	*GDS* Moderate-Severe	*n* = 38 84.68 (-) 58-100	*GDS* Moderate-Severe	Standard care Third group = humanoid robot	NPI & APADEM-NH & AI	****
Phase 2	Pilot RCT	Spain (1)	Pet Social Robot - PARO	*n* = 42 84.7 (-) 59-101	*GDS* Moderate-Severe	*n* = 32 84.7 (-) 59-101	*GDS* Moderate-Severe	Standard care Third group = real dog	NPI & APADEM-NH & AI	
Moyle et al. (2017)	Cluster-RCT	Australia (9)	Pet Social Robot - PARO	*n* = 138 84 (8.4) -	*RUDAS* 6.5 (6.5) Severe	*n* = 137 85 (7.1) -	*RUDAS* 8.3 (7.2) Severe	Standard care Third group = plush toy	Observed Emotion Scheme	***
Tappen & Williams (2009)	RCT	America (1)	Therapeutic Conversation	*n* = 15 83.8 (7.45) 73-100	*MMSE* 10.60 (6.99) Mild-Severe	*n* = 15 90.26 (5.95) 73-100	*MMSE* 12.26 (7.43) Mild-Severe	Standard care	ADRD Mood Scale	***
Hsieh et al. (2010)	RCT	Taiwan (2)	Reminiscence Group Therapy	*n* = 32 77.25 (10.49) 60.0-95.0	*CDRS* Mild: 18 (62.1) Moderate: 11 (37.9)	*n* = 29 77.90 (5.60) 60.0-95.0	*CDRS* Mild: 23 (71.9) Moderate: 9 (28.1)	Standard care	AES	***

Author (Year) = Article identified from hand-searching; QA = Quality Appraisal; MMAT = Mixed Methods Appraisal Tool; RCT = Randomised Controlled Trial; NRIS = Non-Randomised Intervention Studies; MT = Music Therapy; MSSE = Multi-sensory Stimulation Environment; CDRS = Clinical Dementia Rating Scale; GDS = Global Deterioration Scale; MMSE = Mini Mental State Examination; RUDAS = Rowland Universal Dementia Assessment Scale; NPI (NH) = Neuropsychiatric Inventory (Nursing Home); APADEM-NH = Apathy Scale for Institutionalized Patients with Dementia: Nursing Home version; AI = Apathy Inventory; AES = Apathy Evaluation Scale; NOSGER = Nurses’ Observation Scale for Geriatric Patients; ADRD = Alzheimer’s Disease Related Disorders. QA rated using the MMAT: *’s = number of criteria met out of 5 possible items. Note: demographic characteristics for any studies that included a third group were comparable to those of the intervention group.

1.4.2.4 Apathy/DB Measures As specified in the inclusion criteria, all 13 studies reported measures of apathy; ten studies used psychometric measures whereas the other three used observational measures that inferred apathy (e.g., emotional withdrawal). Of the ten studies that used psychometric measures, five used the Neuropsychiatric Inventory (NPI; a broad measure of DB); two used specific measures of apathy (Apathy Evaluation Scale (AES)); one used both broad and specific measures of apathy (NPI; Apathy Inventory (AI) and the Apathy Scale for Institutionalized Patients with Dementia (APADEM-NH)); and the final two used psychometric measures with at least one item that inferred apathy (Alzheimer' Disease and Related Disorder (ADRD) mood scale and the Nurses' Observation Scale for Geriatric Patients (NOSGER)).

Cut-off scores to distinguish between 'healthy' adults and those with apathy are available for all measures however, cut-offs to further distinguish level of severity (as is reported for dementia above) do not appear to exist for the current measures. Some measures include a rating of severity (e.g., NPI) however, the current studies only reported these in relation to their total distress level (e.g., frequency x severity).

1.4.3 RE-AIM Framework Outcomes

The aim of this study was to determine what strategies have been used to facilitate implementation of non-pharmacological interventions for apathy related dementia within residential care settings, how robust these strategies are according to the RE-AIM framework (Glasgow et al., 2019), and how this information could inform future intervention planning. **Fig. 1.3** shows the total number of studies that reported measurable information on each of the five RE-AIM dimensions (Reach, Effectiveness, Adoption, Implementation, Maintenance) required for effectively supporting translation of research into practice; 'Maintenance' was the lowest reported dimension in this review.

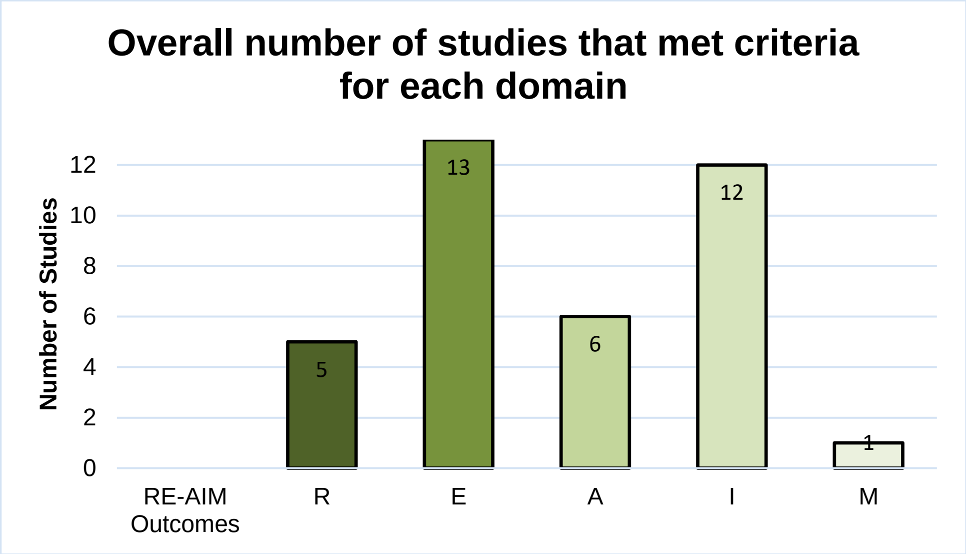


Fig. 1.3: Bar chart showing the number total number of studies that provided information to meet criteria within each dimension of the RE-AIM framework

Table 1.2 provides a full overview of the information available for each of the RE-AIM domains for all included studies.

Table 1.2: Overview of information related to the RE-AIM framework within included articles

Author	Reach	Effectiveness	Adoption	**Implementation** (F= facilitators; B= barriers)	Maintenance	Total RE-AIM Criteria Met
MUSIC						
RE-AIM Criteria Met?		✓		✓		2
Ragilo et al. (2010/2012)	**Proportion of sample who completed:** ***Study* =** 88.3% ***Intervention condition*** = 86.7% ***Reasons for non-completion of intervention:*** death, transfer to hospital (hip fracture), transfer to another nursing home	NPI scores were significantly reduced after one cycle of a music intervention compared to controls. Effect due to significantly lower scores for delusions, agitation, and apathy **E.S:** *d* = 0.63 (medium)		***Adherence/Fidelity:*** Followed MT principles ***Adaptations:*** Use of 3 cycles of MT – one month intervention followed by one month 'wash out' period x3	There was no difference between groups one month after the last cycle ended	
RE-AIM Criteria Met? Y/N	✓	✓	✓	✓		4
<u>Hsu et al. (2015)</u>	***Target****:* 2 care homes – 128 beds 76 assessed for eligibility (59.4%). 17 met criteria (22.4% of those assessed for eligibility; 13.3% of target) ***Proportion of target willing to participate =***	As NPI scores in the control group increased, NPI scores decreased in the MT group. Baseline vs 3months **E.S:** *d* = 1.44 (large) Baseline vs 5months **E.S:** *d* = 1.69 (large)	10/12 staff (83 %) across 2 care homes met inclusion criteria. 100% gave consent 1 drop-out (personal reasons) – 90% completed	***Adherence/Fidelity:*** Residents attended 75.11% of available sessions (mean = 15/22) **F** – High level of acceptability of intervention from staff	Interventions effects remained after 2 months	

	22.4% of those assessed for eligibility; 100% of those who met criteria **Proportion of sample who completed:** ***Study =*** 66.7% of those who met criteria; 22.4% of those assessed for eligibility ***Intervention condition =*** 66.7% of those allocated to intervention ***Reasons not willing to participate:*** NA ***Reasons for non-completion:*** 3 died	Baseline vs 7months **E.S:** *d* =2.32 (large)	**Qualitative Feedback** 100% intervention group staff reported positive effects and recommend MT for PWD	and resident's next of kin **B** – 5 sessions missed on average due to: resident illness, therapist illness, resident asleep, resident declining attendance **B** – 11 occurrences of resident choosing not to attend **B** – 33.3% of ppts not accepting of physiological sensors ***Adaptations:*** Flexibility with session numbers – offer 19 instead of 22 sessions to ppt consenting late		
RE-AIM Criteria Met?	✓	✓	✓	✓	✓	5
Murphy et al. (2018)	***Target:*** Assisted Living Facility housing 75 residents with ADRD 35 asked to participate (46.7%) ***Proportion of target willing to participate*** = 46.7% of target; 100% of those asked	Initial mood – depressed/withdrawn for 70% of participants 62% showed improved mood after personalised music intervention Qualitative reviews of behaviour – general	100% of care homes purposely targeted participated At end of 8-month assessment period all medical technicians in the facility were	**F** – focus on residents with ADRD let staff see personalised music as an intervention rather than just an activity **F** – Care staff internal to home implemented with support of visiting student volunteers – helps to maintain	Intervention program now in its 4th year Accounts need to budget for broken/lost devices/music purchases etc.	

	Proportion of sample who: ***Consistently completed intervention =*** 57.14% of those asked; 26.7% of target sample ***Reasons not willing to participate:*** NA ***Reasons for non-completion:*** Turnover high due to death or discharge – steady state of 20 enrolled	increase in emotional expression Normally sedentary residents started smiling, foot-tapping, engaging with visitors, for example **E.S:** NR	actively participating in the program	**B –** Finding balance between availability of devices and security **F/B –** Need to ensure music personalised and refreshed regularly – participants would get less responsive **F/B –** Major expenses = upfront costs for ipods, headphones and storage	Website for PML allows for regular sign up of volunteers Managing staff turnover – increased use of student volunteers for short amount of time	
RE-AIM Criteria Met?	✓	✓		✓		3
<u>Tang et al. (2018)</u>	***Target:*** 1000 bed residential nursing facility. Potentially eligible = 150 (15%) ***Proportion of target willing to participate =*** 80% of those eligible Met criteria = 77 (7.7%) **Proportion of sample who completed:** ***Study*** = 7.5% of target; 97.4% of those eligible ***Intervention condition =*** 100%	Apathy scores (AES) were significantly lower post intervention **E.S:** NR There were no significant differences in apathy between baseline and 3 months in the control group		***Adherence/Fidelity*** 94.6% of ppts completed all sessions. 5.4% missed one due to illness		

	(2 missed one session due to illness but unclear if included in final analysis) ***Reasons not willing to participate:*** 23 residents refused ***Reasons for non-completion:*** 1 admitted to hospital for hip fracture					
RE-AIM Criteria Met?		✓	✓	✓		3
D'Aniellllo et al. (2021)	**Proportion of sample who completed:** ***Study*** = 100% ***Intervention condition*** = 100%	Significant time by group interaction where NPI frequency/severity was significantly lower in the experimental group than the control group after intervention **E.S:** $\eta_p^2 = 0.26$ (large) Significant time by group interaction where NPI distress was significantly lower in the experimental group than the control	100% care staff in the facility agreed to attend the activities programmed throughout the intervention	***Adherence/Fidelity:*** Study conducted respecting Gerdner et al. (2005;2017) protocol **F** - An individualised approach allows for bypassing cognitive impairment severity		

		group after intervention **E.S:** $\eta_p^2 = 0.22$ (large)				
RE-AIM Criteria Met?		✓		✓		2
Dahms et al. (2021)	***Target***: Three nursing homes (212 PWD in total). ***Residents chosen by staff who provided consent*** = 15.1% No indication of total number eligible **Proportion of sample who completed:** ***Interventions***= 83.3% of those eligible ***Reasons not willing to participate***: NA – participants chosen by care home staff ***Reasons for non-completion:*** 5 early deaths	Scores of apathy (NOSGER) at the end of intervention had decreased more in people who had high usage of the MT interventions than those how had low usage. **E.S:** NR		***Adherence/Fidelity: U***sed manualised study protocols monitored for adherence as part of another study ***Acceptability*** **F -** Group MT and music with movements rated best and frequently used **F** – TBMI promotes autonomy, time-independent access, even for those who cannot participate in groups **B** - TBMI interventions used less than personnel-guided interventions due to health problems, forgetting existence of music interventions, tendency to retreat, motor restlessness **B** – Challenges using technology – not	No significant effects found after 4 weeks	

				adapted to the operability of PWD ***Adaptations:*** Flexible with number of people in MT group		
Multi-Sensory Stimulation Environment (MSSE)						
RE-AIM Criteria Met?		✓	✓	✓		**3**
Anderson et al. (2011)	***Target:*** 176 bed facility. No mention of how many met criteria 12 asked to participate (6.81% of target) **Proportion of sample who completed:** ***Study/intervention* =** 75% of those asked to participate Dropout rates not clearly described	Cited as previously evidenced to be effective for apathy Proportion of disturbed/disengaged behaviours was lower 6 minutes after Snoezelen session compared to being in the common area prior to the session (*n*=9 –trend level significance) No difference on level of engagement between time 1 and time 2 No significant difference of engagement levels between locations at time 1 and time 2	100% of care homes purposely targeted participated 14 staff agreed to support intervention. Total number eligible not reported	**B** – Lack of time and competing work demands **B** – expensive equipment **B –** MSSE too small **B** – Sessions being scheduled - impromptu sessions when residents were agitated would be preferred **F** – Staff saw and enjoyed benefit of 1-1 time – developing relationships **F** – range of items available in room made it easier for staff to run sessions	No staff used MSSE after intervention ended	

		E.S: NR				
RE-AIM Criteria Met?		✓		✓		2
Maseda et al. (2014)	**Proportion of sample who completed:** ***Study*** **=** 86.7% ***Intervention condition*** = 90% ***Reasons for non-completion of intervention:*** 1 dropped out	NPI-NH total scores were significantly reduced in the MSSE and Activity group between pre-, mid- and post-trial time points (no differences between these groups) **E.S:** NR		***Adherence/Fidelity:*** Reported following protocol **F** – Requires little intellectual or physical demands ***Adaptations:*** Flexibility within the standardisation Relatives of ppts interviewed to identify hobbies, interests, and taste	NPI-NH total score significantly increased post intervention for MSSE and control groups (no difference between these groups) **E.S:** NR	
RE-AIM Criteria Met?		✓		✓		2
<u>Sánchez et al. (2016)</u>	**Proportion of sample who completed:** ***Study*** **=** 84.4% ***Intervention condition*** = 81.8% ***Reasons for non-completion:*** 4 deaths, 1 drop-out (activity group)	NPI scores were significantly reduced in the MSSE group compared to the activity group from pre-trial to post-trial **E.S:** η_p^2 = 0.24 (large) No significant effects between MSSE and control groups		Same as Maseda et al. (2014)	Significant effects disappeared at follow-up (2 months later)	
PET-ROBOT THERAPY						

RE-AIM Criteria Met?	✓	✓		✓		3
Valenti Soler et al. (2015) **PHASE 1** Control vs Human social robot vs animal social robot **PHASE 2** Control vs animal robot vs real animal	**PHASE 1** ***Target:*** NH total 156 PWD ***117 willing to participate (75%)*** **Proportion of sample who completed:** ***Study*** = 64.7% of target; 86.3% of those willing ***Intervention condition =*** 100% of those signed up ***Reasons not willing to participate:*** None given ***Reasons for non-completion:*** 22 died, 2 acute illness, 2 transferred to another care home, 1 withdrew consent **PHASE 2** ***Target:*** NH total 156 PWD ***123 willing to participate = 78.8%***	**PHASE 1** Statistically significant decrease in apathy scores (APADEM-NH) after the intervention for animal robot group compared to controls **E.S:** NR Significantly lower scores (NPI-Apathy) for the humanoid robot compared with controls **E.S:** NR **PHASE 2** No significant effects for apathy were found		***Adherence/Fidelity:*** Protocol devised for this study – first to assess animal robot, humanoid robot, and trained therapy dogs as potential tools for therapy **B –** Currently no therapists who specialise in therapy using robots ***Adaptations:*** Use of robot instead of real animals Sessions designed to accommodate 4 levels of dementia severity (previous studies = severe only)		

	Proportion of sample who completed: ***Study*** = 70.5% of target, 94.0% of those willing ***Intervention condition =*** 100% of those signed up ***Reasons not willing to participate:*** None given ***Reasons for non-completion:*** 12 died, 9 moved, 1 withdrew consent, 3 illness or absence					
RE-AIM Criteria Met?		✓	✓	✓		3
Moyle et al. (2017)	Number of total eligible residents in all care homes not indicated ***Proportion willing to participate in whole study***= 93% ***Assigned to pet-robot intervention:*** 155 PWD from 9 care homes – 19 to not receive intervention ***Proportion willing to participate* = 91.6**%	Pet-robot group significantly more verbally engaged than plush toy group **E.S:** *d* = 0.29 (medium) Pet-robot group significantly more visually engaged than plush toy group **E.S:** *d* = 0.61 (medium)	Government accredited care facilities within 100km radius of Brisbane – *n = 37* 28 facilities eligible. All 28 approached and 100% took part	***Adherence/Fidelity:*** PARO group received intervention 25.8 times (on average) out of 30 (86%) **F –** interventions scheduled when levels of agitation etc. normally highest **F** – Intervention can be implemented wherever the resident is	No evidence of sustainability of effects 5 weeks after intervention	

	Proportion of sample who completed: ***Intervention condition*** = *87.5%* ***Reasons not willing to participate:*** 13 Refused/unavailable ***Reasons for non-completion:*** 2 died, 2 palliative	Pet-robot group significantly greater reductions in neutral mood than control group (no difference between PARO and plush toy) **E.S:** d = -0.18 (small)		***Adaptations***: Non-facilitated individual sessions - previous studies used facilitators Duration and frequency of sessions decided based on pilot work		
OTHER						
RE-AIM Criteria Met?		✓		✓		2
Tappen & Williams (2009)	**Proportion of sample who completed:** ***Study* =** 83.3% ***Reasons for non-completion:*** 3 died (1 before pre-test, 2 before treatment completed), 3 illness, 1 refusal to be tested Not indicated whether these participants were previously allocated to control or experimental condition	Apathy scores (ADRD) after the intervention were significantly lower whereas scores in the control group stayed the same **E.S:** η_p^2 = 0.15 (large)		**B** – Intervention requires therapists with specialist training but access to mental health services limited in long-term care settings **B** – Frequent sessions with mental health services may not be cost-effective **B** – Need for care staff to have specialist training ***Adaptations:*** Modified counselling sessions but not specified in which way		

RE-AIM Criteria Met?	✓	✓	✓	✓		4
Hsieh et al. (2010)	***Target***: Two nursing homes (99 bed total). Number met criteria not indicated ***66 recruited for intervention*** (66.7%) **Proportion of sample who completed:** ***Study*** **=** 90.9% of those recruited ***Intervention condition*** = 84.8% of those recruited to intervention condition ***Reasons not willing to participate:*** None given ***Reasons for non-completion of intervention***: 4 withdrew consent, 1 died.	Apathy scores (AES) significantly lower in experimental group after intervention for *Behaviour* domain **E.S:** NR and *Cognition* domain **E.S:** NR Apathy Emotion scores (AES) NOT statistically different after intervention, within the experimental group	100% of care homes purposely targeted participated	***Adherence/Fidelity:*** Protocol implemented as planned **F** – No harm caused by life review; some reported experiencing pleasure while completing this ***Adaptations:*** Trial implementation in care home Activities included designed for suitability with elderly residents living in long-term care. Ensured brightly lit sizeable space, warm and relaxed atmosphere.		

RE-AIM criteria defined in Fig. 1. E.S = Effect Size; NR = Not Reported; *d* = Cohen's *d* (small = 0.2, medium = 0.5, large = 0.8 (Cohen, 1988)); η_p^2 = partial eta squared (small = 0.01, medium = 0.06, large = 0.14 (Murphy & Myors, 2004)); MT = Music Therapy; TBMI = Technology Based Music Interventions NPI (NH) = Neuropsychiatric Inventory (Nursing Home); APADEM-NH = Apathy Scale for Institutionalized Patients with Dementia: Nursing Home version; AI = Apathy Inventory; AES = Apathy Evaluation Scale; NOSGER = Nurses' Observation Scale for Geriatric Patients; ADRD = Alzheimer's Disease Related Disorders.

1.4.3.1. Reach The 'Reach' column in **Table 1.2** shows, where applicable; the percentage of people targeted for intervention, percentage of people who met criteria for the intervention, percentage of people who completed the study, and percentage of people who were allocated to the intervention condition and completed it.

Only five out of 13 papers (Murphy et al., 2018; Tang et al., 2018; Hsu et al., 2015; Valenti Soler et al., 2015; Hsieh et al., 2010) reported reach as outlined in the RE-AIM framework. These five papers targeted specific care home(s) and outlined the total number of residents living in these care homes in comparison to how many were recruited. One of these five papers also reported the total number of residents eligible for the intervention (people with dementia and apathy/DB; Hsu et al., 2015), and two provided this information as well as the number of participants who were eligible and went on to complete the study (Tang et al., 2018; Murphy et al., 2018). **Fig. 1.4** represents the difference in the levels of this information. For example, all the details from Tang et al. (2018) and Murphy et al. (2018) provide us with a fuller reach context; not only can we see the proportion of people who require the intervention but also the proportion who were accepting of it.

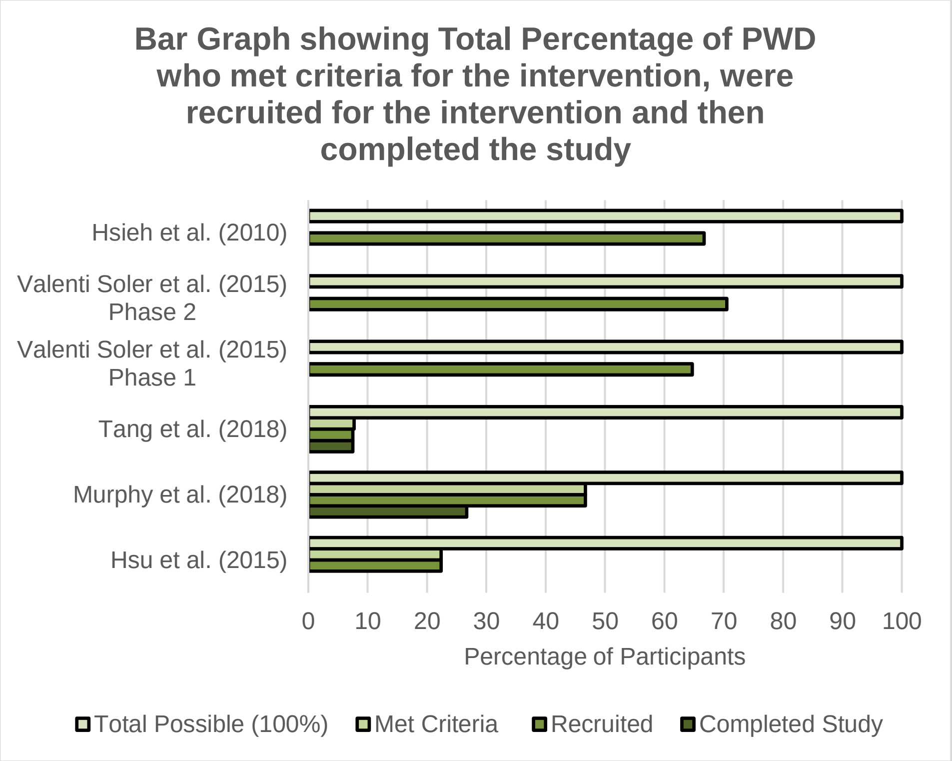


Fig. 1.4 Bar graph detailing 'reach': the total percentage of participants who could participate in the study (100%); the total percentage of participants who met criteria for the study; the total percentage of participants who met criteria and were then recruited into the study; and the total number of people who were recruited and completed the study

The remaining papers did not indicate the total number of PWD eligible for inclusion however, information can still be derived about the proportion of people who were asked to participate and went on to complete an intervention. On average, 85.5% of participants recruited in the current studies completed the assigned intervention. In relation to the specific types of interventions included, the retention rates were also high; 82.3% for music interventions, 82.3% for MSSE interventions and 95.8% for robot-pet therapy interventions. Although retention rates were high, there were several people who dropped out and some consistent reasons were noted for this within the current populations: deaths, physical illness (mild or serious), hospitalisation due to fractures, transfers to other care homes, and generally just 'dropping out'.

1.4.3.2 Effectiveness Apathy outcomes were used to assess 'Effectiveness'. Thus, as part of the inclusion criteria, all included papers reported a reduction in apathy (or a general measure that includes apathy) associated with the intervention implemented in the current or previous papers using the same intervention. Only six of the 13 eligible studies included effect size information; three using Cohen's *d,* three using partial eta squared (η_p^2).

Music Six papers discussed implementation of music interventions. 3/6 of these reported effect sizes, ranging from medium-large, and all sampled residents with moderate-severe dementia who received a one-to-one music therapy intervention. Raglio et al. (2010; 2012) evidenced lower NPI scores for delusions, agitation, and apathy after a one-month cycle of music therapy (twelve 30-minute sessions) compared to controls ($d = 0.63$; medium). Hsu et al. (2015) demonstrated lower NPI scores for PWD who received a music therapy intervention once a week (30 minutes) for five months compared to controls; these effects were seen three months ($d = 1.44$; large), and five months ($d = 1.69$; large) after baseline, as well as two months after the intervention ended ($d = 2.32$; large). D'Aniello et al. (2021) reported that NPI frequency x severity ($\eta_p^2 = 0.26$; large) and distress ($\eta_p^2 = 0.22$; large) was significantly lower for those who received music therapy compared to controls after the intervention (eight weeks; 30 minutes, twice-weekly sessions).

Tang et al. (2018) also assessed the effectiveness of a music therapy intervention (50 minutes, three times a week over three months); finding apathy scores in people with mild-moderate dementia to be significantly lower post-intervention but the size of this effect was not reported (Tang et al., 2018). However, this is one of only three studies that assessed the impact of the intervention using an apathy specific outcome measure.

Dahms et al. (2021) implemented a range of music interventions for residents who presented with severe dementia on average. Some of these interventions were personnel-led; i.e., interactive interventions (e.g., group and individual music therapy, group music movement) whereas others were purely technology-based with no personnel guidance; i.e., receptive interventions (e.g., background music, individual radio) and they all varied in length (4-168 sessions; 45 minutes – 6 hours; three times a day – fortnightly). Their findings indicated that those who had a higher usage of the interventions had lower apathy scores than those who had low usage, and that the most frequently used interventions were those guided by staff/therapists (e.g., group music therapy) as opposed to those that were technology-based and had minimal staff facilitation (e.g., individual radio). However, no effect size information was available to describe these effects and there seemed to be no control for the range of dementia severity presentations in the sample, as reflected in the MMAT QA.

Murphy et al. (2018) implemented a personalised music intervention over a period of eight months which was assessed using observational measures. In 70% of observations prior to using the music intervention, PWD were described as depressed/withdrawn. 62% of the observations of PWD after they had engaged with the intervention were described as having improved mood; this was identified by a general increase in emotional expressions, smiling, foot-tapping, and engaging with visitors. Severity of dementia was not reported for this sample and thus, not controlled for.

Multi-Sensory Stimulation Environments (MSSE) Three papers used a MSSE intervention; Maseda et al. (2014) and Sánchez et al. (2016) compared the intervention with an activity and control group whereas Anderson et al. (2011) used a repeated measures design whereby all residents engaged in an MSSE and garden activity intervention. Only Sánchez et al. (2016) reported an effect size, demonstrating a large effect ($\eta_p^2 = 0.24$) in a sample of residents with severe dementia. This effect related to significantly reduced NPI scores for the MSSE group between the pre- (week 0) and post-trial (week 16) timepoints when compared to the activity group. There was also evidence of improved dementia severity scores with MSSE compared to activity and control groups (Sánchez et al., 2016). Maseda et al. (2014) also described significantly reduced NPI scores between pre- (week 0), mid- (week 8) and post-trial (week 16) timepoints for residents with mild-severe dementia in both MSSE and activity groups however, these groups were not significantly different from each other and at two-month follow up the MSSE group showed an increase in NPI scores. Anderson et al. (2011) reported a drop in observed disengagement behaviours in residents with severe dementia immediately after the MSSE intervention (in comparison to behaviours observed prior to the intervention) however, this only resulted in a trend level of significance. Low participant numbers were cited as a potential reason for this however, this paper received the lowest QA score (out of all eligible papers) due to lack of controlling for dementia severity (confound), <80% sample completing the intervention and staff perhaps not using the intervention as intended.

Pet-Robot Therapy Valenti Soler et al. (2015) reported that people with mild-severe dementia who participated in an animal (PARO the seal) and humanoid robot intervention (adapted for dementia severity level) had significantly lower apathy scores than controls however, the size of this effect was not reported. Furthermore, no differences in apathy were found in the second phase of the same intervention where PARO, real animal and control groups were compared; instead, there was some evidence of higher hallucinations in the PARO and dog groups compared to control. Moyle et al. (2017) assessed the observed impact of an intervention using the same animal robot (PARO the seal) on residents with severe dementia, compared to a plush toy and control group. Residents participating in the PARO intervention were described as more verbally (d = 0.29; medium) and visually (d = 0.61; medium) engaged than those in the plush toy group. This same study also demonstrated greater reductions in neutral mood in the PARO versus control group (d = -0.18) however, there was no statistical difference found between PARO and the plush toy group on this variable.

Other Tappen and Williams (2009) found that apathy scores were significantly lower after a therapeutic conversation intervention (η_p^2 = 0.15; large; three-weekly, 30-minute sessions over four months) in residents with mild-severe dementia, whereas controls assessed over the same time frame showed no difference in these scores.

Hsieh et al. (2010) used a group reminiscence therapy intervention for residents with mild-moderate dementia severity and reported significantly lower apathy scores in both the behaviour and cognition domains after this intervention (12, 40-50minute sessions over three months). No difference was found in the emotion domain of this apathy measure.

1.4.3.3 Adoption 6/13 studies reported some element of adoption rates on either the organisational or individual/staff level.

Organisational Level All studies noted the care homes they recruited from but to be classed as a measure of adoption they also needed to state either, that there was specific reason to target these care homes, or if there were any other care homes/organisations targeted (i.e., be clear if the care home(s) included were 100% of the care homes targeted). 4/13 studies indicated that they purposely targeted specific care home(s) and that 100% of these participated (Murphy et al., 2018, D'Aniello et al., 2021, Anderson et al., 2011, Hsieh et al., 2010, Moyle et al., 2017). Moyle et al. (2017) conducted an RCT for a robot-pet therapy that targeted all care homes within 100km of Brisbane (*n* = 37) and 100% of eligible homes participated (*n* = 28).

Staff Level 4/13 studies (three music therapy interventions (Hsu et al., 2015; Murphy et al., 2018; D’Aniello et al., 2021) and one MSSE intervention (Anderson et al., 2011)) reported information related to adoption/intention to adopt. Anderson et al. (2011), Hsu et al. (2015), and D’Aniello et al. (2021) all noted that 100% of the staff who were approached and eligible to participate, supported the intervention. However, there was no indication of the total number of staff available within these settings that could provide this support. Murphy et al. (2018) had applied the RE-AIM framework to their study to investigate implementation of a personalised music intervention supported by medical technicians within the care home. They reported, in relation to adoption, that all staff in these job roles were continuing the implementation of this intervention after the 8-month research period. 100% of the participating staff within Hsu et al.'s (2015) music therapy study reported that they found the music interventions implemented had a positive impact on PWD, and that they would continue to recommend this as an intervention for their residents.

Staff implemented or facilitated interventions in 3/13 studies (Anderson et al., 2011, Dahms et al., 2021, Murphy et al., 2018). Some demographic information was reported for 2/3 staff samples however, as they presented different characteristics (e.g., job-role, age, etc.), we were unable to infer any potential patterns relating to implementation factors. 11/13 studies were delivered at least in part by external professionals, but no demographic or adoption information was reported for this population.

Adoption could not be evaluated against the RE-AIM framework in the remaining seven papers. Although some studies had included interventions that were delivered by trained therapists external to the home, none addressed the potential adoption rates for this population (i.e., willingness to continue the intervention or total number of therapists that would be able to facilitate adoption). However, Tappen and Williams (2009) did discuss the difficulties for administrations to support the costs associated with external professional intervention facilitation, which may impact on adoption.

1.4.3.4 Implementation

Adherence/Fidelity Although all papers reported a research protocol, only five referenced manualised intervention protocols that pre-dated the current papers

(Anderson et al., 2011; D'Aniello et al., 2021, Maseda et al., 2014, Sánchez et al., 2016, Tappen & Williams, 2009), and none used formalised measures to assess fidelity/adherence to research or intervention protocols within the current study. Three studies reported their protocol was implemented as planned (Maseda et al., 2014, Sánchez et al., 2016, Hsieh et al., 2010) and three reported proportions of sessions attended against those offered (Tang et al., 2018, Hsu et al., 2015, Moyle et al., 2017); one reporting <80% attendance (Hsu et al., 2015).

Adaptations Adaptations were difficult to determine in some studies due to the lack of protocol adherence reporting. However, as identifying adaptive components within interventions are crucial for determining successful implementation (Rapaport et al., 2017), we took an inclusive approach to categorising implementations (i.e., rating any detail indicative of adaptation/personalisation within the paper).

Nine out of 13 studies referred to an adaptation, but these were poorly reported on overall. Only three studies had specific aims about whether intervention adaptations were associated with positive behavioural outcomes within residential care (Raglio et al., 2010; 2012, Moyle et al., 2017, Valenti Soler et al., 2015, Hsieh et al., 2010). Raglio et al. (2010; 2012) adapted the length of treatment time of a music intervention; assessing effectiveness of the intervention being delivered in one-month cycles with one-month breaks as opposed to the traditionally implemented continuous delivery (Raglio et al., 2010;2012). They reported significant behavioural effects between baseline and post-intervention but found most of this change to occur after one month; scores returning towards baseline after two further cycles (Raglio et al., 2012). Moyle et al. (2017) assessed the effectiveness of a non-facilitated version of robot-pet therapy intervention and demonstrated higher levels of social engagement in participants. Valenti Soler et al. (2015) assessed the effectiveness of a pet-robot intervention with sessions adapted based on the participants' dementia severity level (e.g., more cognitively demanding tasks for mild dementia versus more sensory based tasks for severe dementia) and found a small effect for pet-robot versus control group (phase 1) but no effects comparing the pet-robot with a humanoid robot or real dog in phase 2. These results suggest adaptation by severity of dementia did not meaningfully change apathy outcomes. Hsieh et al. (2010) designed and assessed a reminiscence group therapy for use in residential care settings, noting that adaptations were related to content (Hsieh et al., 2010) but did not explicitly state how this varied from 'traditional' forms of this therapy. The intervention seemed to be effective for 2/3 sub-scales of apathy.

The three MSSE intervention papers noted ways in which the intervention was personalised; speaking to family of the participant to ensure activities aligned with their interests. This personalisation seems to be a slight adaptation to the original protocol referenced in Maseda et al (2014) and Sánchez et al. (2016) papers which relied on the staff perspective of resident interests (Baker et al., 2001), but this was not clearly indicated as an adaptation within the current papers.

Two papers reported being flexible regarding shortening or extending aspects of the interventions to meet needs of the participants; Hsu et al. (2015) offered a reduced number of sessions to a participant that consented late in the active research phase (due to health difficulties) and Dahms et al. (2021) reported expanding group numbers outwith their research protocol.

Barriers and Facilitators Barriers and facilitators were reported in 11 studies. The range of barriers reported included factors such as cost, resource, staff training and resident illness; with the most commonly reported barrier being dropout related to illness factors such as forgetting, sleeping, transfer of care or hospitalisation. Barriers specific to interventions led by therapists included need for care staff to have specialist training to continue use, high costs associated with bringing in mental health professionals, and the limited crossover between mental health and residential care services. Others were more specific to the interventions.

Barriers in relation to music interventions within the current studies were mostly related to the technology used to implement them; people being less receptive to technology-based interventions than personnel-guided interventions, difficulties working and storing music devices, and need to regularly refresh music choices. There were many facilitators for music intervention including: staff having high acceptance of it as an intervention, seeing personalised music as an intervention rather than just another activity, easy accessibility, and facilitation of technology when it worked well, and the possibility for it to be individualised regardless of level of cognitive impairment. One study found use of volunteers helped facilitation (Murphy et al., 2018).

One of the biggest barriers noted for MSSEs was the expense of the equipment needed (e.g., the room itself as well as activities within the room). Furthermore, in one study it was reported that this room was too small (Anderson et al., 2011). Lastly, staff found the scheduling of using this room difficult, preferring to be able to use it on a more impromptu basis. However, staff also reported that competing work demands and shortness of time made it difficult to use this intervention at all (Anderson et al., 2011). Facilitators included staff enjoying the opportunity to develop their relationship with the resident through one-to-one time, the room being able to cater to PWD with a range of physical and intellectual capabilities due to the low demand of the ‘tasks’, and the range of items available to support facilitation from staff (Anderson et al., 2011).

The main barrier for pet-robot therapy was that there are no therapists who specialise in using these tools however, the facilitators include being able to employ this intervention wherever the resident is and whenever their distress increases (Moyle et al., 2017).

1.4.3.5 Maintenance None of the included studies assessed the long-term implementation and/or effects in line with the RE-AIM framework (i.e., 6-months after intervention) however, six did attempt to assess effects at a specified follow-up period (range = 1-3 months). Within these time frames, one study evidenced sustained effects (Hsu et al., 2015), whereas the remaining five found no effects at follow-up.

Murphy et al. (2018) discussed maintenance in relation to the costs needed to sustain a personalised music intervention. The up-front costs as well as the replacing of lost/broken devices were previously noted as a barriers but budgeting has allowed for this intervention to be run over a period of four years over which time they had to manage a complete staff turnover within the organisation (Murphy et al., 2018). Furthermore, they have a website in which volunteers can regularly sign up to support the intervention (Murphy et al., 2018).

Anderson et al. (2011) reported trend level effects of MSSE interventions and no evidence of maintenance; staff reported at interview that nobody had used the MSSE since the intervention period two months prior.

1.4.4 Quality Appraisal (QA)

All studies were scored for QA using the MMAT due to varying methodological approaches; nine RCTs, three NRIS and two mixed methods (one RCT and one NRIS for the quantitative portion). Overall reporting was good; only 22% of all items were rated as ‘can’t tell’ and most studies receiving three- or four-star ratings. For RCT designs, ratings were dropped due to reporting make it hard to determine if randomisation was performed appropriately, if the assessors were blinded to the interviews and if the participants adhered to the intervention. All three NRIS dropped points due to not appearing to account for the confounder of dementia severity and 2/3 lost one-star due to questions of adherence of the intervention as intended. The qualitative components for both mixed methods studies were rated highly. QA ratings for each study are included in **Table 1.1** and any aspects of the studies that reduced these ratings are discussed within the current synthesis (**1.5 Discussion**) within the context of: a) how they may limit our understanding of how apathy interventions were implemented in the first place, and b) any conclusions we can make about their effectiveness.

1.5 Discussion

1.5.1 What strategies have been used to facilitate implementation of the reviewed apathy interventions?

There were a wide range of implementation facilitation strategies identified in the current review. These included: consideration of how samples were targeted/recruited; the sample characteristics (e.g., dementia and apathy severity) and whether these led to adaptations in implementation; the type of interventions chosen for use; how the effectiveness of interventions were measured (both in terms of outcome measures and duration of effects); the intervention/research protocol and adherence or adaptation thereof; staff and organisation’s/stakeholder’s willingness to engage with the intervention; and consideration of longer-term effects of the intervention as well as how they may be supported to continue.

1.5.2 How effective are these strategies for facilitating implementation according to the RE-AIM process evaluation framework?

The majority of studies included in this review did not accurately report ***Reach***: the proportion of people willing to participate in the intervention in relation to the total possible target population. This measure is important as it allows for a more accurate indication of participation rates as well as the number of people that require a certain intervention (Glasgow et al., 2019). For example, Tang et al. (2018) reported only 7.7%

of residents required an intervention for apathy within a 1,000-bed home whereas Hsieh et al. (2010) identified 66.7% of a 99-bed home requiring intervention. Thus, a larger care home does not necessarily require higher provision for a specific intervention and smaller care homes may have higher demand. Future studies should ensure accurate reporting of reach during/after implementation to ensure effective use of resource (Glasgow et al., 2019) and improve chances of better facilitation. Appropriate recording of reach and dropout rates can also highlight common barriers that implementation may need to overcome.

Effectiveness within this review refers to the impact of interventions on apathy outcomes. Five different types of intervention were included and, although by nature of the inclusion criteria they demonstrated some evidence of improvements in apathy outcomes, the intervention type seemed to impact on the nature or degree of these effects.

Music interventions were generally found to be related to lower apathy ratings compared to controls but varied in the sub-type of intervention used. Broadly, five (including the addendum) implemented interactive interventions (which required active resident participation and direction from facilitators, e.g., music therapy) and two used receptive interventions (where participation was more passive, e.g., individual radio). Previous research has suggested that receptive versus interactive music interventions may be more effective for DB (Soufineyestani et al., 2021) and a previous umbrella review reported that out of all evaluated non-pharmacological interventions, receptive music interventions are the most consistently reported to be effective for apathy (Cai et al., 2020). In the current review, Dahms et al. (2021) found that residents were more likely to use interactive interventions that required input from staff however, the QA of this and Murphy et al. (2018; the other included study that used a receptive intervention) was average (three stars) to low (one star), with both losing ‘points’ for not controlling for confounds such as dementia severity. Nevertheless, further research comparing the effectiveness of receptive versus interactive interventions (whilst controlling for dementia severity) as well as assessing the level of staff input required and resident engagement, would help to inform appropriate intervention selection.

MSSE and pet-robot therapy interventions were generally linked to reductions in apathy over time but, there was some evidence that apathy outcomes were not significantly different between these interventions and a third group which offered alternative stimulation (e.g., garden activity or a plush toy). A previous review for MSSE reported similar findings (MSSE being no more effective than staff reading to a PWD, Lorusso & Bosch, 2018) and a previous review for pet-robot therapies has described the interventions effectiveness as heterogeneous (Hirt et al., 2021). Furthermore, quality ratings were lower for the included MSSE studies (one- to three-stars; MMAT) and lack of high-quality studies for multi-sensory stimulation interventions has been previously noted as an issue within the wider literature base (Cheng et al., 2019). MSSE and pet-robot therapy interventions were included based on the outcome of a recent umbrella review surmising that the overall evidence base showed more consistent support for their effectiveness for apathy than other interventions (e.g., psychomotor therapy, Cai et al., 2020) however, the current results suggest a need to further assess these interventions effectiveness for treating apathy using more rigorous methods, and with a higher level of reporting quality.

Only single studies were included for reminiscence group therapy and therapeutic conversation thus no comparisons of effectiveness could be made. Nevertheless, recent reviews appear supportive for their use as long as they are appropriately targeted to the client’s level of cognition (Woods et al., 2018; Shoesmith et al., 2022) however, both of the included studies received a quality rating of three stars (due to limitations with randomising procedures and Tappen and Williams (2009) not providing a description of adherence to their study protocol) making it difficult to determine if the appropriate adaptations were made to allow for this level of targeting. Further investigation into the use of these therapies for treating apathy are required however, within this review, we have identified some general limitations within the literature (see below) that may need to be addressed before meaningful conclusions regarding effectiveness for non-pharmacological interventions more generally can be drawn.

Firstly, only six out of the 13 included studies reported effect sizes for their results, and these were split between reports of Cohen's *d* and partial eta squared. This lack of consistency in reporting made it difficult to determine the size of the individual intervention effects or make any meaningful comparisons across interventions. Future studies should ensure regular and consistent reporting of this statistic.

Secondly, there was a large range in outcome measures (both psychometric and observational) used to assess intervention effects. Apathy as a symptom, is often not well understood by both the PWD or their carer's, and is not commonly researched (Dening et al., 2021). Furthermore, there is no 'gold standard' measure for apathy and these have generally not been well-validated in PWD (Mast et al., 2022) however, recently the Apathy Evaluation Scale (AES) has been recommended for use in this population (Burgon et al., 2021) and is thought to measure its three components (cognition, emotion and behaviour). Using this measure, Hsieh et al. (2010) found that attending reminiscence group therapy was associated with apathy in the behaviour and cognition but not emotional domains. This finding indicates that interventions may differentially impact distinct elements of apathy and could highlight the need for multiple or complex interventions to address and assess effectiveness in relation to each of these outcomes. However, further research is needed to determine if this is a common finding.

7/13 of the studies reviewed used the NPI. However, due to low reliability and construct validity ratings, the NPI has been recommended for use as a screening tool only (Burgon et al., 2021), calling into question how accurately these studies are or could ever assess apathy. Furthermore, it has been suggested that optimum measures of apathy should also include an observational component (Burgon et al., 2021); these are associated with higher construct validity and allow for additional evaluations of the interactions between the behaviours and the environment (Madsø et al., 2021). Only three included studies used observational methods but due to variations in the measures and study designs used, the results were not comparable.

Additionally, none of the current measures allow for an accurate rating of apathy severity; apathy presence is determined by a specified cut-off with higher scores generally indicating higher severity of apathy, but there are no cut-ffs for categorising severity for those who meet clinical criteria for apathy as there is for dementia, for example. However, higher apathy ratings have previously been associated with higher dementia severity (e.g., Tang et al., 2018) suggesting that studies sampling residents with more severe dementia may also be addressing more severe instances of apathy. It will be important for future studies to identify and agree on a tool that accurately measures apathy (and potentially its severity), to allow for more meaningful and comparable evaluations of implementation effectiveness.

Thirdly, consideration of dementia severity could be important for determining and influencing the effectiveness of intervention implementations due its association with decreased cognitive and behavioural functioning (Valenti Soler et al., 2015). However, although 12/13 of the included studies measured dementia severity, how this information was used differed between them (e.g., sample description, outcome measure, etc.). In relation to QA, none of the three NRIS controlled for the potential confounding effects of dementia severity; one sample had an average rating of severe and another moderate-severe, but both demonstrated large ranges and no consideration was given to whether individuals outwith the average performed/engaged any better or worse with the interventions. Valenti Soler et al. (2015) attempted to adapt the facilitation and format of the sessions of their pet-robot therapy intervention based on severity of dementia however, no breakdown of results was reported with regards to the effectiveness of this adaptation. Furthermore, they attributed lack of an effect on apathy in the second phase of this intervention to be related to the more severe presentations of dementia found in people in residential care; suggesting there is less potential for any non-pharmacological intervention to affect change outwith the mild-moderate range of dementia severity (Valenti Soler et al., 2015). However, there was some evidence that MSSE could be more effective for people with severe dementia; offering a stimulating activity that places less demand on the resident (Sánchez et al., 2016). Future research would benefit from more explicitly assessing the impacts of various interventions on residents with varying severity levels of dementia as well as considering apathy severity; this may inform delivery of interventions in relation to dose-response as well as overall resident suitability.

Adoption relates to willingness to commence or participate in an intervention. Where adoption rates were reported for organisations/settings, 100% participated, suggesting there is potential for residential care settings to be highly receptive to interventions. Conversely, Hsu et al. (2015) reported low completion rates of a music intervention (67%) despite 100% of staff reporting it to have clear benefits and that they would recommend its use. This suggests that implementation studies will need to ensure sampling of representative populations of staff (e.g., proportion of whole care home or staff group) as well as management/organisations in order to accurately assess the likelihood of adoption (Glasgow et al., 2019). Furthermore, given that communication between stakeholders and staff is a common problem for translational research in dementia (Gitlin et al., 2015), inclusion of extra strategies to facilitate this within implementation protocols may be needed.

Tappen and Williams (2009) suggested that care home staff are an under-utilised resource within intervention implementation; this also seems to be the case in the current review (2/13 studies using care staff to help support interventions). Training and support for staff to facilitate interventions may lead to higher adoption rates however, staff buy-in should also be considered. For example, Villar et al. (2021) noted that staff who perceive apathy as ‘less disruptive’ than agitation may not be as invested in (and subsequently willing to adopt) interventions for apathy; they may therefore benefit from educational support on the poor outcomes associated with apathy in dementia (Rajkumar et al., 2016). Similarly, job/staffing pressures may also impact staff buy-in (Gitlin et al., 2015). Furthermore, although previous studies have reported benefits of external professionals/experts providing support to care staff, this can be a costly resource and not always welcomed by in-house staff (Surr et al., 2019, Tappen & Williams, 2009). Future implementation studies could therefore benefit from assessing staff’s attitudes towards apathy alongside the intervention’s effectiveness, as well as ensuring intervention demands are balanced with other job pressures and training needs.

Implementation relates to protocol adherence, facilitators and barriers and reported/measured adaptations of interventions. Three from the reviewed studies reported purposive adaptation, offering clear contributions to translational research. For example, designing and finding evidence for a non-facilitated pet-robot therapy session (previously conducted as facilitated sessions, e.g., Valenti Soler et al., 2015) is effective for improving social engagement (Moyle et al., 2017), and that lower apathy scores are associated with a music therapy intervention spanning one month (previous interventions up to eight months; Raglio et al., 2010;2012), highlights potentially effective interventions that are less intensive for caregivers. Evidence for effective interventions relying on less resource (e.g., shorter treatment time lengths or less reliance on facilitators) with clear protocols (and amendments thereof) may peak interests at policy/organisational levels and increase chances of funding for further implementation (Gitlin et al., 2015). However, further research is needed to determine if these findings can be replicated.

Hsu et al. (2015) and Dahms et al. (2021) reported slight adjustments to elements of their protocol based on current participant need (e.g., offering fewer sessions to accommodate health needs). These are important considerations given that high dropout rates due to illness were commonly reported barriers within the included studies, and that these rates are likely to continue given the identified trend for decreasing health and functioning within the PWD population (Barker et al., 2021). Future studies may benefit from a combined approach in which delivery/targeting of interventions is both adapted for dementia severity (as in Valenti Soler et al., 2015) and allows for the more reflexive adjustments (as above) required to support the diverse needs of PWD living in residential care (Rajkumar et al., 2016). However, transparent reporting of these strategies will be required to enhance replication and ensure intervention effectiveness is not compromised (Gitlin et al., 2015).

Transparency of reporting in relation to protocol adherence was a general issue within the current review; a finding that was also evidenced in the QA where 5/10 of included RCTs and 2/3 NRIS dropped points due to difficulties determining intervention adherence. This lack of reporting has been noted in other studies of non-pharmacological interventions for DB (Scales et al., 2018, Rapaport et al., 2017) and made it difficult, within the current review, to determine: what adaptations were made, the subsequent potential effectiveness of these, and the possibility of future replication. This reporting issue may be due to a general lack of manualised protocols in the literature for non-pharmacological interventions (e.g., Soufineyestani et al., 2021, Moreno-Morales et al., 2020, Saragih et al., 2021). Regardless, this issue is a threat to high quality implementation, and it will be important for future research to develop and consistently report specific intervention protocols for apathy interventions within residential care settings. This practice will ensure consistent and comparable delivery which, in turn, may help identify facilitators and barriers. Furthermore, following frameworks such as the ‘FRAME approach; a system for coding adaptations’ (Wiltsey Stirman et al., 2019) may facilitate consistent reporting and help to clarify areas for further change.

A range of barriers and facilitators were identified but a common consideration was how accessible and easy staff believed the intervention was to implement or access; for example, whether the space was big enough, items for supporting the intervention were easily found and stored, a range of items were available, and the interventions could be implemented as and when required (e.g., when residents became more distressed). Due to the level of dependency residents with dementia are likely to have on staff (Anderson et al., 2011, Helleberg & Hauge, 2014) these factors will be crucial to ensure translation of interventions into residential care.

According to the RE-AIM framework, to determine real-life effectiveness, ***Maintenance/***long-term effects need to be studied after at least 6-months (Glasgow et al., 2019). However, none of the included articles assessed the effects of interventions more than two months after their completion. Of those that did assess effects up to two months post-intervention, only a small proportion of them found evidence to suggest maintenance of the intervention effects; suggesting a need to re-evaluate how these interventions were implemented and, possibly, the treatment options for apathy.

Although effectiveness was not assessed after six months, the personalised music intervention reported in Murphy et al. (2018) had been running for four years at the point of evaluation. They cited managing ongoing costs/budgeting (e.g., for storage and devices) and steady recruitment of volunteers as key factors for the maintenance (Murphy et al., 2018). Further research will be needed to determine if the longevity of this intervention can be backed up with evidence of prolonged effectiveness for apathy in residential care.

On a staffing level, and similarly to adoption, continued staff buy-in is also a key consideration for maintenance. Anderson et al. (2011) reported that, despite initially high proportions of staff adoption rates, the MSSE installed in the care home was not used once in the two months after the intervention assessment period (despite the high costs associated with initial set-up); noting lack of time and high job demands as reasons. Future studies may benefit from using more qualitative in addition to quantitative methods to fully explore and consider these pressures when planning and designing interventions if maintenance is expected (e.g., Anderson et al., 2011).

1.5.3 How could findings from this review inform future implementation planning for apathy interventions?

Although a lot of limitations were noted in relation to the reporting across the eligible studies, our review of these papers revealed several strategies and considerations that could inform future planning for delivery of apathy interventions in PWD in residential care. Firstly, careful evaluation of the population's need for an intervention as well as reporting of successful completion rates may help ensure appropriate use of interventions (Glasgow et al., 2019). As apathy is known to be difficult for staff to recognise in PWD and can present differently across individuals (Massimo et al., 2018), this evaluation may include developing standard processes within care home settings to identify and measure apathy, adapt care plans to indicate the need for non-pharmacological intervention, and continually monitor levels of apathy to determine intervention effectiveness. Secondly, development and accurate reporting of protocols and adherence thereof are needed for all intervention studies (e.g., Soufineyestani et al., 2021, Moreno-Morales et al., 2020, Saragih et al., 2021) to encourage reliable and consistent implementation, as well as allow for more accurate and comparable evaluations of their effectiveness. Development of these protocols should also coincide with training for care staff where appropriate. Thirdly, more thoughtful adaptations focused on targeting specific characteristics of the population (e.g., dementia severity, health complications, etc.) and pressures of the setting (e.g., job demand, environmental constraints, etc.) may improve the overall effectiveness of interventions and ensure optimal use of resources (Raglio et al., 2010;2012, Valenti Soler et al., 2015). Up-to-date care plans and knowledge of the individual residents as well as the care home setting will be important to inform these adaptations thus, input from care staff will be essential. Fourthly, further consideration of staff's/organisation's capabilities in addition to attitudes and support for the intervention (perhaps using qualitative methods, e.g., Anderson et al., 2011; Hsu et al., 2015) may highlight training needs for staff as well as facilitate better adoption and maintenance rates of interventions within the care home setting. Finally, there is still a need for future process evaluations to assess long-term effects of non-pharmacological interventions within residential care settings (Boersma et al., 2015). However, an important consideration, particularly for apathy, is that there may be a fundamental need to re-evaluate the treatment options and assess this using outcome measures that more appropriately capture the presentations of apathy that occur within these settings and populations (Mast et al., 2022).

1.5.4 Limitations

A possible methodological limitation of this review is related to the search strategy. A total of 4,461possible articles were identified which was reduced to eight (plus one addendum) articles after applying inclusion criteria. A further five were included from searching reference lists, meaning that just over a third of the reviewed articles were not picked up by the created search. Furthermore, it is likely that additional eligible papers within the literature were not identified from the hand-search. On review of the titles and abstracts, it was identified that articles were missed due to not including search terms clearly related to process evaluation. However, this limitation may be due to under/inaccurate reporting of process evaluations within the literature (Glasgow et al., 2019) and highlights the need for accurate reporting of such methods (Pinnock et al., 2017). Furthermore, the small numbers of papers more generally eligible for inclusion may be related to wider problems within the literature base, such as the under-researching of apathy (Dening et al., 2021) as well as limited use of outcome measures that accurately assess this outcome (e.g., not just NPI; Burgon et al., 2021).

In recognition of the under-researching of apathy in the literature, this study included research which used measurements more widely assessing DB, despite this not being their primary focus, if there was a potential for findings to be applicable to apathy (e.g., broad measures of DB which included apathy specific items as well as measures used to assess apathy-related symptoms). However, as these general measures incorporate a wide range of DBs, and apathy can be difficult to identify in PWD (Massimo et al., 2018), this approach may have added additional noise to the data making it difficult to determine if all of the interventions or implementation strategies are directly effective for apathy. Therefore, the current findings may not be solely related to apathy and more studies are needed to further assess factors of facilitation that may be apathy specific. Regardless, the focus on residential care settings for PWD should mean that findings will be useful for a range of DB within these settings.

In order to focus on the evaluation of factors which promote successful implementation, we only included studies using interventions demonstrated as effective for apathy. However, this narrow definition of effectiveness may not be entirely in keeping with the RE-AIM framework which highlights the importance of assessing wider as well as potentially negative outcomes (Glasgow et al., 2019). As studies with null findings may still provide important information about implementation strategies within the dementia residential care population, future reviews may benefit from reviewing papers on comparable interventions that were not effective in relieving apathy.

Furthermore, given the heterogeneous findings in relation to effectiveness for non-pharmacological interventions to reduce apathy in the literature base, our methods to limit our search to most effective interventions (i.e., as reported in Cai et al., 2020) may have been flawed. Other non-pharmacological interventions may also warrant inclusion in future reviews.

1.6 Conclusion

Although there are a number of non-pharmacological interventions that are considered to be effective for symptoms of apathy exhibited by PWD (Cai et al., 2020), translating such interventions into daily practice has been a long-standing difficulty within residential care (Gitlin et al., 2015) and the factors that may help to implement them are not well understood (Boersma et al., 2015). The aim of this study was to determine and evaluate the use of these interventions in relation to the RE-AIM process evaluation framework and use this to inform future intervention implementation planning within residential dementia care. Despite limited research in this field (13 studies met the eligibility criteria) and inconsistent implementation and/or reporting standards in relation to the RE-AIM framework, several methods which could improve implementation were described.

However further process evaluation studies would help to determine more specific translational strategies for specific interventions. It will also be important for future research to continue to improve the non-pharmacological treatment options for apathy as well as their implementation into residential care settings.

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Chapter 2: Major Research Project

Apathy in people with dementia: A survey study of care home staff perceptions and experiences of burnout

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2.1 Plain Language Summary

Background: For people with dementia (PWD), apathy is a common symptom and is linked with higher and earlier death rates (van der Linde et al., 2017). Furthermore, apathy and other distressed behaviours (DB) are cited as causes of distress/burnout for care staff (Isik et al., 2019). Staff's beliefs/perceptions related to these DB have been found to account for some of the level of stress/burnout experienced (Mills & Rose, 2011) however, this has not been directly tested in relation to apathy in PWD.

Aims & Questions:

a) Do staff exposed to more severe presentations of apathy have higher levels of stress/burnout?

b) If staff perceptions/beliefs about this apathy are more negative (e.g., they can control their behaviour but don't), does this relate to, and possibly account for, their higher levels of burnout?

Methods

***Participants**:* Care staff working directly with PWD who present with apathy within older-adult residential care settings.

Recruitment: Care staff were recruited from care homes in the NHS Highland area via a study poster delivered to and displayed in their place of work.

***Consent**:* Participants were provided with the study information sheet and, as no identifiable information was collected, informed consent was assumed through their completion and submission of survey responses.

***Design of Study**:* A survey consisting of a range of self-report questionnaires measuring; the severity of apathy staff were exposed to, staff confidence in responding to apathy, how balanced staff perceive the carer-resident relationship to be, staff's beliefs about how controllable resident's apathy is, staff empathy for apathy, and staff levels of stress/burnout.

Data Collection: Staff completed the self-report questionnaires via an online survey platform or on paper.

Ethical Issues*:* Staff may have found some of the questions distressing. As responses did not contain any personally identifiable information, it was not possible for direct clinical support to be provided however, signposting to appropriate services was made in the participant information sheet. All responses were received by researchers via online platform or freepost to ensure anonymity. As response rates were expected to be low, a prize draw incentive was used.

Practical Applications & Dissemination*:* This research provided us with information about staff's beliefs and level of understanding of apathy in PWD and how this may impact their level of stress at work. This information also allowed us to make suggestions about measures that may be needed to support staff as well as highlight any training needs.

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2.2 Abstract

Background: Around 90% of people with dementia (PWD) exhibit neuropsychiatric/behavioural problems. Apathy is a very common distressed behaviour (DB) in dementia and is linked to increased caregiver burden. DBs, more generally, are often associated with higher levels of staff burnout, and perceived levels of both DB and staff burnout may also be related to the attributions/perceptions staff have of these behaviours. However, few studies have assessed the impact of apathy in PWD and their formal carers.

Objective: To determine if a) greater apathy severity is associated with higher levels of staff burnout, and b) whether the apathy-burnout risk is mediated by staff attributions of apathy.

Methods: Participants were a convenience sample of care staff (*n* = 82) working with PWD within NHS Highland care homes, assessed using a cross-sectional survey. The survey included self-report questionnaires measuring exposure to apathy, experiences of burnout, and attributions in relation to apathy (controllability, reciprocity, empathy, and self-efficacy). Demographic and descriptive measures about the care setting were also collected.

Results: Parallel mediation analyses were conducted in RStudio (v4.0.3) using the PROCESS macro with bootstrapped sampling. Greater severity of apathy exposure was associated with higher levels of burnout in staff ($\beta = 0.233$, $t(1,66) = 1.955$, $p = 0.055$; 95% bootstrapped CI = 0.001 – 0.020) and seemed to be mediated by staff's attributions of reciprocity ($\beta = 0.054$; 95% bootstrapped CI = 0.009 – 0.136); greater imbalance within the carer-resident relationship was related to higher levels of burnout.

Discussion: Evidence of a link between severity of apathy in PWD and burnout in residential carers may highlight further training and support needs for staff. Reciprocity as a mediator for this relationship also indicates a potential modifiable pathway in which training and wellbeing interventions can be developed and implemented. However, the

current study results are preliminary and should be interpreted with caution until replicated in larger, more representative samples.

2.3 Introduction

Over 400,000 people in the UK live in care homes (NIHR, 2020) and approximately 70% have some form of dementia (Alzhemiers.org.uk, 2021). Around 90% of people with dementia (PWD) experience neuropsychiatric/behavioural problems (e.g., agitation, delusions, apathy; Cerejeira et al., 2012, Rajkumar et al., 2016). These behaviours, henceforth referred to as Distressed Behaviours (DB; James et al., 2011), are closely associated with an increase in caregiver distress/burden (Isik et al., 2019, Cerejeira et al., 2012). Furthermore, increased care burden has been linked to poorer caregiver-patient relationships which, in turn, can also worsen neuropsychiatric symptoms in people with dementia (PWD) (Isik et al., 2019). Apathy, is one of the most commonly experienced DB in PWD (Malpetti et al., 2021, van der Linde et al., 2017, Mukherjee et al., 2017); prevalence estimates range from 17-90% (average = 36% in Rajkumar et al., 2016). Apathy is linked to increased premature mortality risk (van der Linde et al., 2017), faster progression of dementia (Breitve et al., 2018), and high caregiver burden in a range of populations (β=0.21–0.45; Feast et al., 2016, Mukherjee et al., 2017, Rajkumar et al., 2016, Godinho et al., 2008), but reductions of apathetic symptoms have also been evidenced in response to a number of non-pharmacological interventions (Cai et al., 2020). Nevertheless, apathy is one of the least well understood symptoms of dementia (regarding diagnosis, impact, and intervention) and is often overlooked in research (Dening et al., 2021). Thus, improved understanding of apathy and its impact on carers in residential settings, will not only help determine how to best support care staff and promote wellbeing (Wong et al., 2020) but may also lead to better outcome for PWD displaying DB, including apathy (Dening et al., 2021).

Staff Burnout Staff/caregiver burnout is a widely acknowledged problem for carers of PWD and/or DB. Prevalence rates range from 22–69% in health care workers (Costello et al., 2019a; Westwood et al., 2017), with varying levels of severity (Duffy et al., 2009, El Haj et al., 2020, Costello et al., 2019b); even higher rates have been evident since the onset of COVID-19 (79%; Ferry et al., 2021). Some of this spread may be attributable to variations in the cut-off scores used on psychometric measures of burnout (Costello et al., 2019b). Nevertheless, experiences of burnout have been linked to a range of adverse impacts on staff wellbeing (e.g., anxiety, frustration) and result in lower quality of care for PWD (El Haj et al., 2020). Various caregiver factors are associated with burnout (e.g., age, gender, job role, etc.), but evidence for these associations has been inconsistent (Costello et al., 2019b) and because these are generally unmodifiable, they do not lead to obvious treatment options. Thus, investigation of modifiable factors associated with burnout, such as staff attitudes and coping strategies (Baharudin et al., 2019, Cavanaugh et al., 2020), is needed. Furthermore, it is not clear from the literature how burnout is linked to exposure to DB, such as apathy; highlighting the need for this relationship to be explored and any viable factors for intervention to be identified.

Distressed Behaviours, Staff Attributions and Burnout Feast et al., (2016) reported that individual DB differentially impact caregivers, highlighting apathy as a symptom that informal caregivers considered distressing. Higher ratings of burnout in formal carers have been linked to severity of agitated/aggressive behaviours in PWD (Costello et al., 2019b) however, to our knowledge, the potential link between apathy severity and formal carer burnout has not been investigated; such investigations are important given the established high prevalence of apathy in PWD (Breitve et al., 2018) as well the links between poorer caregiver wellbeing and worse outcomes in PWD (Isik et al., 2019, Lwi et al., 2017). Thus, investigations of potential causal relationships between caregiver distress and specific symptoms of DB may help to both facilitate the design of more effective interventions for these symptoms (Feast et al., 2016) as well as support care staff.

Although further understanding of the link between DB (such as apathy) and burnout are needed, it has also been suggested that exposure to “challenging” or hard to manage behaviours alone is not enough to explain the variance in burnout that is seen in caregivers (Feast et al., 2016; Wong et al., 2021). Feast et al*.,* (2016) suggested that the variability in caregivers’ responses to specific DB as opposed to DB in isolation may account for the variation in caregiver outcomes. Furthermore, Wong et al (2021) proposed carer specific psychological factors may mediate the relationship between apathy severity and carer wellbeing. Attribution theory, for example, posits that our emotional responses to a person’s behaviour, and in turn our propensity to help, are influenced by how we attribute the cause of the behaviour itself (Weiner 1985). Weiner (1985) noted three dimensions in which causal attributions can be categorised: whether the cause is internal external to the person; whether the person is thought to be able to control the behaviour; and whether the behaviour is temporary or likely to endure. In a sample of carers for people with intellectual disabilities, staff attributions have been linked to carers understanding, existence and maintenance of DBs (van den Bogaard et al., 2020) and some attributions (namely; controllability, reciprocity, empathy, and self-efficacy) about DB were investigated as mediators between ‘challenging behaviour’ severity and staff burnout (Mills & Rose, 2011). Although people with learning disabilities and those with dementia have many different needs, there are similarities in the support needs of caregivers who face DB (Heller et al., 2018). It is possible that attributions of these behaviours may also have similar impacts on caregivers in both populations. However, the relationship between DB, staff attributions of DB, and staff burnout have not been examined using mediation analyses in contemporary studies of PWD, nor has it been assessed using the specific DB of apathy.

Controllability In line with attribution theory, over-estimates of how much control people with dementia or intellectual disabilities have over their behaviour have been evidenced to alter carer responses. Carers who do believe that PWD have greater control over their behaviours are likely to offer less support to the PWD in their care and experience more strain (Singleton et al., 2017, Tarrier et al., 2002). Specific to apathy, qualitative analysis highlighted feelings of frustration in staff when they believed that PWD were capable of doing tasks but were choosing not to (Baber et al., 2021). Qualitative analysis also suggested that the more socially unacceptable a behaviour was (a possible proxy for severity), the more likely staff were to believe that the resident should be able to control it (Rapaport et al., 2018). Controllability was also proposed as a mediator for the relationship between severity of “challenging behaviours” in people with intellectual disabilities and staff burnout (Mills & Rose, 2011) and requires quantitative investigation in samples of formal carers for PWD.

Reciprocity Reciprocity refers to the level of perceived balance in a relationship. In line with the Schaufeli et al.’s (1996) dual-level model of social exchange and burnout, previous studies indicate that care staff may feel that they exert more effort into their relationships than they receive, and that this imbalance of effort elevates burnout reactions (Thomas & Rose, 2010, Duffy et al., 2009, Rose et al., 2010), and leads to poorer care (Thomas & Rose, 2010). Lack of reciprocity in the carer-resident relationship has been associated with emotional exhaustion in carers for people with intellectual disabilities (r=0.29; Thomas & Rose, 2010). This association was not statistically significant in dementia carers however, the directions of the correlations in this study suggested that lower reciprocity was linked with higher burnout (r=0.22; Duffy et al., 2009); lack of a significant effect was possibly due to the small effect size in the sample of 61 care assistants. Qualitatively, feelings of distress in family caregivers of PWD showing apathy have been associated with low reciprocity (de Vugt et al., 2003, Fyrand, 2010). Furthermore, advancement of dementia (which has been associated with increased severity in apathy; Breitve et al., 2018) has been associated with lower reciprocity in informal carers (Graham & Bassett, 2006). Further testing of the apathy-reciprocity association in formal carers is needed.

Empathy Han (2020) noted that empathy is an important characteristic for people taking on dementia care roles; greater carer empathy has been associated with better levels of care, less DB, and lower levels of staff burnout in formal settings. The relationship between higher empathy and lower levels of burnout has also been evidenced in a review of studies from a range of healthcare settings (r= -0.17-0.24; Wilkinson et al., 2017). There is limited research into the relationship between severity of DB and levels of empathy in staff. However, similarly to controllability, qualitative analysis indicated that staff seemed to be less understanding of more socially unacceptable behaviours (Rapaport et al., 2018); suggesting that more severe distress behaviours can be more difficult to empathise with. Further tests of the relationship between apathy in PWD and staff empathy, as well as the impact of both constructs on staff burnout are needed.

Self-Efficacy Self-efficacy theory (Bandura, 1997), a component of Bandura's social cognitive theory, states that the likelihood of performing a behaviour is dependent on the individual's belief that they have the capacity to perform the behaviour to the level they desire; interpersonal self-efficacy beliefs have been related to prosocial behaviours (Alessandri et al., 2009). Zhang et al. (2014) found that self-efficacy is a partial mediator for the relationship between DB and caregiver burden in spousal carers, and suggested interventions promoting self-efficacy in carers may help to reduce DB. However, this analysis was conducted using the now, less favoured, Sobel test method of mediation (Hayes, 2013). Higher self-efficacy has been linked with lower levels of burnout in dementia carers within residential care home (Duffy et al. 2009; emotional exhaustion, r=-0.53) and ward settings (Kokkonen et al., 2013; emotional exhaustion, r=-0.20). Practical support for this relationship also comes from a UK care home survey, evidencing that staff who have had more dementia care training reported using more hopeful and person-centred approaches (Islam et al., 2017). Assessing the relationship between apathy in PWD and staff self-efficacy within formal dementia care settings may help identify whether development of apathy-specific training is warranted.

2.3.1 Aims and Research Questions

2.3.1.1. Aims Although apathy in PWD is linked to caregiver burden (Isik et al., 2019), given the prevalence of apathy in PWD 17-90% (average = 36% in Rajkumar et al., 2016) and the varying rates in staff burnout (Ferry et al., 2021, El Haj et al., 2020, Costello et al., 2019a, Costello et al., 2019b), it seems that exposure to apathy on its own is not enough to result in staff experiencing burnout. This information suggests that consideration of mediators is warranted (Duffy et al., 2009). Based on the foregoing review, we propose four mediators (related to staff attributions/perceptions) that have enough support in the literature to warrant investigation: controllability, reciprocity, empathy, and self-efficacy. The current study therefore sought to determine if a) the severity of apathy in PWD (as observed by care home staff) was associated with higher levels of staff burnout, b) if staff attributions/perceptions of apathy were associated with apathy exposure and/or burnout, and c) conduct exploratory analysis into whether the apathy-burnout relationship is mediated by these staff attributions/perceptions (see **Fig. 2.1**). Understanding these relationships may help inform staff training and support needs within dementia care staff; potentially by identifying modifiable pathways for interventions to be applied.

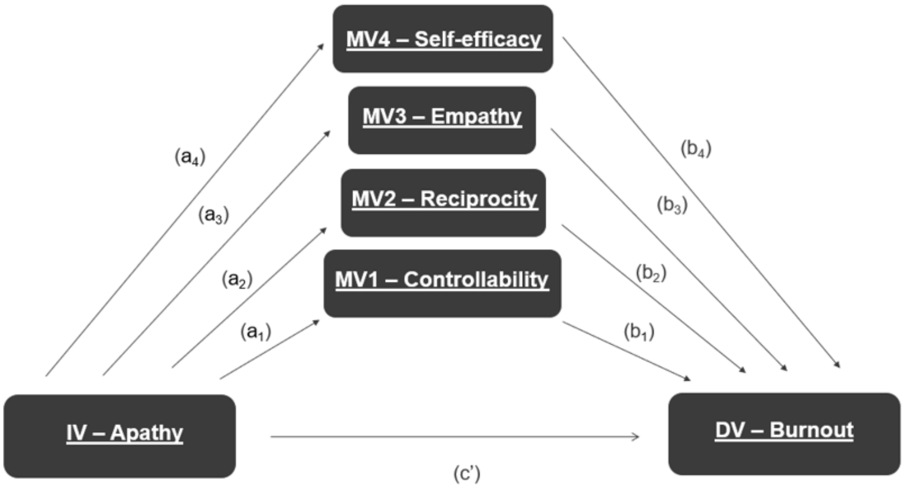

Fig. 2.1: Diagram showing the proposed correlation and mediation pathways to be tested for each mediator. IV = Independent variable; MV = Mediator variable; DV = Dependent variable

2.3.1.2. Research Questions and Hypotheses These aims resulted in the following research questions:

1) Is there a relationship between the severity of apathy that staff are exposed to in their workplace and the levels of burnout that they report?
2) Is the relationship between apathy severity and burnout mediated by the attributions/beliefs that staff make in relation to apathy.

We hypothesised that more severe presentations of apathy in residents within the current population will be associated with higher scores of staff burnout and that this relationship may be mediated by one or more of the assessed attributions regarding apathy.

2.4 Materials and Methods

2.4.1 Design

Cross-sectional survey of eligible care home staff from all 53 private or NHS care homes across NHS Highland (estimated sample pool = 1,076), using convenience sampling.

2.4.2 Participants

86 survey responses (8% of the estimated total population) were received. Participants had to be care home staff who worked directly with PWD who experience apathy (e.g., nurses, care assistants, and managers/deputy managers but not agency or domestic staff) to be included. Three participants who did not meet these criteria were excluded (*n* = 83), with a further one excluded due to only completing demographic information. The final current sample was therefore*;* 82 individuals ($n_{\text{males}}/n_{\text{females}}/n_{\text{anothergender}}$ = 6/75/1) with a mean age of 44.43 years (S.D = 12.86 years, range = 18-66 years). See **Table 2.1** for full descriptive information. 29 surveys were completed online with the remaining 53 completed on paper. Data was missing at random, for one or more items, in one third (17/53) of the paper questionnaires.

2.4.3 Research Recruitment and Procedures

An informal consultation with key stakeholders (e.g., members of the Stress & Distress team and care home managers) was conducted to inform survey design and decisions about the selection of variables to be measured. The consultation was also used to inform staff training and support needs (e.g., staff attributions and setting factors) and recruitment procedures.

Managers of all 53 residential/nursing care homes in NHS Highland were contacted prior to data collection to determine if they would provide permission for their staff to participate in the study, and to confirm feasibility of the study design (e.g., length of time to complete, survey delivery format). Estimated numbers of available staff within the care homes were also collected at this time (January/February 2022).

Surveys were completed between March-June 2022. Paper copies of the survey were sent directly to the care homes with pre-paid envelopes. Access to the online survey was provided through posters with a QR code directly linking them to the survey (access available via a range of devices i.e., smart phone, tablet, computer, etc.). Posters were either mailed or delivered in person to the care home managers who were asked to display these in staff areas. Uptake was periodically encouraged via staff from the Stress & Distress team who already provided input for the invited care homes (see **Appendix B1**). As an additional incentive for participating, participants were also offered the chance to enter a prize draw to win one of two £20 Amazon vouchers. Entry was available via a link for a separate 'Prize Draw' survey. Winners of the prize draw were drawn and contacted with their prize in July 2022. Within NHS Highland, care homes were subject to lockdowns implemented in line with the government responses to COVID-19. As it was thought that this may have impacted the study response rate, a one-month extension to the data collection period was approved in an attempt to boost responses.

2.4.4 Ethics

The current study was sponsored by NHS Highland Research and Development (R&D) Department (Highland 1798). Ethical approval was received for this study via NHS R&D (IRAS 306679; see **Appendix B2.1**) and the University of Glasgow (College of Medical, Veterinary and Life Sciences (MVLS); application number: 200210059; see **Appendix B2.2**). A participant information sheet was provided for both versions of the survey (see **Appendix B1)** which explicitly stated that as no identifiable information was collected, informed consent was assumed by participant completion and submission of survey responses. All data was collected, stored, and processed in line with the General Data Protection Regulations (2018) and the Data Protection Act (2018).

2.4.5 Materials and Measures

The survey included questions regarding participant demographics and several questionnaires (see below; also see OSF_Survey for the full version of the survey as well as OSF_Protocol for the original measures).

2.4.5.1 Demographics Participants were asked to provide information about; age, gender, ethnicity, educational attainment, job role, hours worked, average sleep per night this week, previous Stress & Distress support with residents, Stress & Distress training completed, length of time worked in care, length of time worked in their current role, number of residents with dementia in their care, as well as how many of these experienced aggression and apathy. Data on staff's beliefs about whether shifts are staffed appropriately, as well as whether their psychological needs were met on shift were also gathered using a Likert scale rating (1 = "Never"; 4 = "All of the time").

2.4.5.2 Independent Variable

2.4.5.2.1 Severity of Apathy Participants were provided with a vignette demonstrating how apathy may typically present in the average PWD. This vignette was based on previous definitions of apathy (e.g., Rajkumar et al., 2016; Apathy Evaluations Scale (α=0.86-0.94) Marin et al, 1991) and distinguished it from depression (see OSF_Survey). Staff were asked to consider PWD within their care whose presentations fit with those described in the vignette and based on these individuals, rate the frequency, difficulty and distress caused by apathy on them. Apathy severity was calculated based on these responses (severity = frequency x (difficulty + distress)) in line with previous apathy rating scales for distress (e.g., Challenging Behaviour Scale, Moniz-Cook et al., 2001 (α = 0.82-0.87); Neuropsychiatric Inventory Questionnaire, Cummings, 1994 (inter-rater reliability = 0.79-0.86)). This resulted in a total apathy score out of 32, where higher scores equal higher severity. No cut-offs were available to categorise level of severity.

2.4.5.3 Mediators - Attributions/Perceptions of Apathy

2.4.5.3.1. Controllability The Controllability Beliefs Scale (Dagnan et al., 2004) is a 15-tem measure created for use with care staff for older adults with “challenging behaviour” (α =0.73-0.92). Participants were asked to rate how much they believe that a statement relates to the person that they are caring for using a 5-point scale (1 = ”Disagree strongly”, 5 = ”Agree strongly”). The current measure was adapted to ask staff to rate these statements in relation to PWD in their care who present with apathy, e.g., “The people in my care who have dementia marked by apathy are trying to wind me up”. Five items were reversed scored thus; a higher score reflects higher agreement with beliefs that the PWD are in control of their behaviour.

2.4.5.3.2. Reciprocity Caregiver reciprocity was measured using an adapted version of the Specific Reciprocity Measure (Van Horn et al., 2001). This nine-item measure assesses the level of investment and outcome for the exchange in the relationship between care staff to the person they care for (five investment, four outcome measures). A reciprocity score was calculated for each respondent by dividing the mean of their investment item responses by the mean of their outcome item responses. A ratio score of 1 indicates a reciprocal relationship; scores >1 indicate a non-reciprocal relationship where the investment is greater than what is received; and scores <1 indicate a non-reciprocal relationship where more is received than given. As the use of ratio scores in linear analyses can bias estimates, scores were made linear by taking the inverse of all scores less than 1 (e.g., 0.25 (or 1/4; mean investment item responses divided by mean outcome item responses) becomes 4 (1 divided by 1/4), in line with Rose et al., 2010).

Thus, the higher the score the less reciprocal the relationship. Reliability ratings in a sample of staff caring for older PWD ranged from $\alpha = 0.73$–0.92 (Duffy et al., 2009; Rose et al., 2010). Both transformed and non-transformed scores of reciprocity were presented.

2.4.5.3.3. Empathy Empathy was measured using an adapted version of the Staff Empathy towards individuals whose Behaviour Challenges Questionnaire (SEBCQ; Hutchinson et al., 2014) which was originally devised for use within the intellectual disability population (reliability ratings of $\alpha = 0.72$ and 0.71 within these samples, Hutchinson et al., 2014; Hastings et al., 2018). The SECBQ has five items scored on a 6-point scale: 1 = "Disagree Strongly"; 6 = "Agree Strongly", e.g., "I can imagine what it might be like to have dementia marked by apathy". Higher scores suggest greater empathy.

2.4.5.3.4. Self-efficacy Staff were asked to indicate their level of confidence, from 0-10 (0 = "Not confident"; 10 = "As confident as I can be"), to respond to apathy displayed by PWD who they work with. This was adapted from similar scales used in previous studies of mental health worker attitudes toward working with people who have psychosis (McLeod et al., 2002).

2.4.5.4 Dependent Variable

2.4.5.4.1 Staff Burnout Staff burnout was measured using the Oldenburg Burnout Inventory (Demerouti et al., 2003). This is a 16-item measure rated on a scale from 1 = "Strongly Agree" to 4 = "Strongly Disagree", with 8 items reverse scored. The OLBI allows for a full-scale measure of burnout (OLBI-FS) as well as two sub-scales: Disengagement (OLBI-D) and Exhaustion (OLBI-E). A mean single index score (ranging from 1-4) was calculated for all three scales with a higher score relating to higher levels of burnout (Delgadillo et al., 2017). The OLBI has high reliability indices ($\alpha = 0.85$) and construct validity in health care worker samples (including nurses in acute geriatric care facilities; El Haj et al., 2020). Previous studies have established cut-off and mean scores for the burnout subscales in UK healthcare professionals: scores >= 2.10 in OLBI-D indicate burnout (M = 2.3); scores >= 2.25 in OLBI-E indicate burnout (M = 2.5; Westwood et al., 2017, Delgadillo et al., 2018). OLBI-D/E scores are described to characterise the current sample however, the outcome measure used was OLBI-FS.

2.4.6 Statistical Analysis

All statistical analyses were conducted in RStudio (v4.0.3). Responses from surveys were downloaded from an online survey platform (Jisc online surveys; https://www.onlinesurveys.ac.uk/) in .csv format and paper responses were input into the same csv. file by hand (EN). At this time survey responses were checked against inclusion criteria and any non-feasible responses were removed (e.g., responding 601 to number of dementia residents in their care). Missed items were entered as “999”, if any items relating to any of the measures that required scoring for the final analyses were missed (i.e., apathy severity, burnout, controllability, reciprocity, empathy, and self-efficacy), the whole measure was removed. Number of rows missing from each of these variables is detailed in **Table 2.1** and **2.4**. Statistical assumptions were tested, and moderate skew was highlighted in some continuous variables as well as some outliers. However, as no data points were over ±3SDs of the mean (e.g., Osborne & Overbay, 2004) and skew statistics indicated that no variables were highly skewed, (>-1/<1; Kim, 2013); no outliers were removed, no data was transformed, and parametric analyses were conducted.

2.4.6.1 Demographics Number, percentage, means, standard deviations and ranges were used to describe: the available demographic variables; basic characteristics of the older people under the care of the respondents; and the independent, dependent and mediator variables analysed within the current study.

2.4 6.2 Mediation Mediation analyses were conducted using the PROCESS-macro for R (v4.1; Hayes, 2013; https://www.processmacro.org/download.html). *A priori* power analyses indicated that 307 responses were required to detect mediation effects for controllability at 0.80 power however, no effect sizes for the other three mediators have previously been reported in the literature. Assumptions for regression were checked prior to these analyses, the variance of the residuals violated assumptions for normality. The percentile bootstrapping method (10,000 samples) was therefore used to account for any violations in the distribution of the sample as well as any issues with power. The current model included four potential mediators (controllability, reciprocity, empathy, and self-efficacy; see **Fig. 2.2**) therefore a parallel four-mediator model was used. Apathy severity was entered as the independent variable and burnout as the dependent variable. No covariates were included due to the aforementioned inconsistencies in the impact of caregiver characteristics in the literature (Costello et al., 2019b), and the statistical power limitations within the sample. Fourteen cases were removed (n = 68) due to incomplete data.

Exploration of demographic/setting characteristics that may impact burnout in the current study were also assessed as below:

2.4.6.3 Differences in Burnout between groups One-way ANOVAs were used to determine if there were any differences in burnout between categorical groups (e.g., job role, education, etc.) within the sample; using Tukey's HSD for post-hoc multiple comparison investigation.

2.4.6.4 Associations with Burnout Relationships between the burnout (DV) and continuous demographic variables were examined using Pearson's correlations.

2.5 Results

2.5.1 Demographics

Full demographic information of the sample can be found in **Tables 2.1** and **2.2**. The majority of respondents were white females who spoke English as a first language. However, response rates were low in this study.

Table 2.1. Demographic information for categorical variables in total sample

Variable	Category	*n* (%)
Job Role		
	Care Assistant	26 (31.7%)
	Nurse	6 (7.3%)
	Senior Care Assistant	29 (35.4%)
	Senior Nurse	6 (7.3%)
	Manager/Deputy Manager	15 (18.3%)
Gender		
	Male	6 (7.3%)
	Female	75 (91%)
	Not Specified	1 (1%)
English as a First Language		
	Yes	76 (93.8%)
	No	5 (6.2%)
Ethnicity		
	White	81 (98.7%)
	Mixed or Multiple	
	Asian or Asian British	
	Black, African, Caribbean, or Black British	1 (1%)
	Other Ethnic Group	
Educational Attainment		
	Secondary	33 (40.3%)
	College	11 (13.4%)
	Undergraduate	26 (31.7%)
	Postgraduate	12 (14.6%)
Training		
	Essentials	36 (44%)
	2-day Stress & Distress	14 (17%)
Staffing Levels are Appropriate?		
	Never	9 (10.9%)
	Some of the Time	39 (47.5%)
	Most of the Time	30 (36.7%)
	All of the Time	4 (4.9%)
Contact With Stress & Distress Team		
	Yes	46 (56.0%)
	No	18 (22.0%)
	Don’t Know	18 (22.0%)

Table showing number and percentage of participants within each categorical demographic variable (*n* = 82)

Table 2.2. Demographic information for continuous variables in total sample

Variable	Range	M	SD
Age (*n* = 77; 93.9%)	18 - 66	44.43	12.86
Years Worked in Current Post (*n* = 82; 100%)	0.08 – 33.17	9.19	8.91
Years Worked with PWD (*n* = 81; 98.7%)	0.66 – 41 years	14.58 years	10.34 years
Number Hours Worked This Week (*n* = 80; 97.6%)	0 - 72	37.61	12.09
Hours Worked Over Contract (*n* = 29; 35.4%)	1.50 – 34.50	12.45	9.50
Number of Hours Access to Activity Co-ordinator (*n* = 80; 97.6%)	0 – 72.50	18.08	19.38
Average Hours of Sleep (*n* = 81; 98.7%)	4 - 9	6.37	1.06

Table showing number and percentage of participants within each continuous demographic variable as well as their means (M), standard deviations (SD) and ranges where appropriate. Average hours of sleep refer to the amount of sleep that staff attained. (*n* = 82)

Information was also collected about the characteristics of the older adults under the care of the participants (see **Table 2.3**).

Table 2.3. Characteristics of the people with dementia (PWD) under the care of the current sample

	M	SD	Range
PWD	17	13	1 – 84
% of Total PWD			
With Apathy	43.41%	29.45%	5 – 100%
With Aggression	36.03%	25.11%	0 – 100%

Mean (M), standard deviation (SD) and range of number of PWD who the respondents care for as well as percentages (mean, standard deviation, and range) of these PWD who also presented with apathy or aggression. (*n* = 79).

The number of PWD under the care of an individual staff member in this sample ranged from 1 to 84 with an average of 17 (SD = 13). Of these PWD, a mean of 43% (SD = 30%) presented with apathy and 36% (SD = 25%) presented with aggression. This is comparable to previous samples in the literature showing higher rates of apathy than aggression in care homes (Rajkumar et al., 2016)

Table 2.4 shows the mean, standard deviations, and ranges of the independent, dependent and mediator variables within the current sample.

Table 2.4. Descriptive Statistics for Independent, Dependent and Mediator Variables

	M	SD	Range
Apathy Severity (IV) (*n* = 77; 93.9%)	13.73	5.86	2 – 32
OLBI-FS (DV) (*n* = 75; 91.5%)	2.40	0.46	1.19 – 3.56
OLBI-D (*n* = 75; 91.5%)	2.20	0.51	1.00 – 3.50
OLBI-E (*n* = 75; 91.5%)	2.61	0.50	1.38 – 3.63
Perceptions of Apathy – Mediators			
Self-efficacy (*n* = 81; 98.7%)	7.70	2.07	2 – 10
Empathy (*n* = 81; 98.7%)	23.46	3.93	15 – 30
Reciprocity: Transformed [non-transformed] (*n* = 81; 98.7%)	0.15 [1.21]	0.21 [0.31]	0.00 – 1.40
Controllability (*n* = 79; 96.3%)	26.53	9.62	15 - 55

n (%) refers to the number and percentage of respondents who had data available for each of these measures out of the total sample of 82. Scores for reciprocity included the transformed score for use in analysis as well as the non-transformed ratio (scores >1 = carers give more than residents; <1 = residents give more than carers) M = Mean; SD = standard deviation.

Burnout is indicated in this sample due to most respondents exceeding the pre-defined cut-offs of 2.18 for OLBI-FS (*n = 54;* 72%), 2.10 for OLBI-E (*n* = 66*;* 88%), and 2.25 for OLBI-D (*n* = 40*;* 53%; Westwood et al., 2017, Delgadillo et al., 2018). Compared with previous UK healthcare professional samples pre-COVID-19, staff scores for the current sample are slightly lower for disengagement (previous M = 2.3) but higher for exhaustion (previous M = 2.3; Westwood et al., 2017, Delgadillo et al., 2018).

Non-transformed scores of reciprocity suggest that, on average, carers perceive that they give more than residents in the carer-resident relationship; indicating a lack of reciprocity (score >1).

2.5.2 Parallel Mediation

There was a significant, positive direct effect of apathy severity on burnout (c' - β = 0.268, t(5,62) = 2.270, *p* = 0.027 ; 95% CI = 0.003 – 0.043); as apathy severity in PWD increases, so does staff burnout when mediators are kept constant (see **Fig. 2.2**). This pathway remained significant after bootstrapping (c - β = 0.028, CI = 0.008 – 0.048).

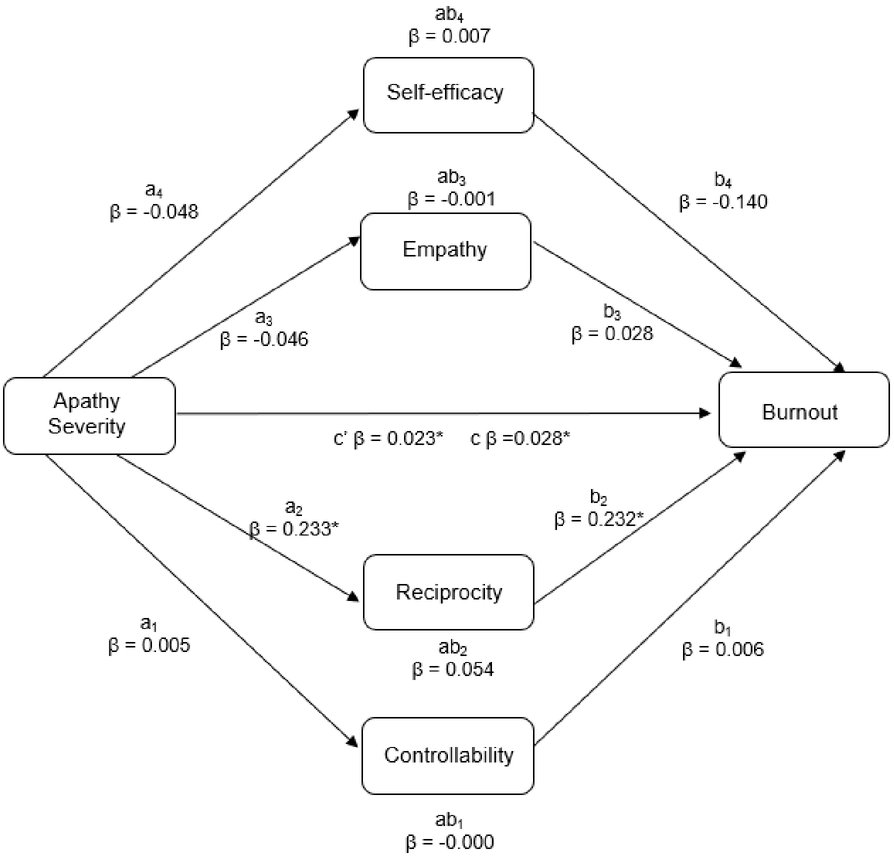

Fig. 2.2: Parallel mediation models. Figure showing the standardised effect sizes of each pathway in the parallel mediation model. * indicates significant effects

The effect of apathy severity on reciprocity between staff and residents (a_4-path) was significant (a - β = 0.233, t(1,66) = 1.955, *p* = 0.055; 95% bootstrapped CI = 0.001 – 0.020); higher levels of apathy in residents were associated with a less reciprocal relationship between staff and the residents in their care. Less reciprocity (i.e., greater relationship imbalance) in this relationship was also significantly associated with higher levels of staff burnout (b_2-path - β = 0.232, t(5,62) =1.941, *p* = 0.057; 95% bootstrapped CI = 0.147 – 1.902). The indirect effect of reciprocity was also significant (ab_2 - β = 0.054; 95% bootstrapped CI = 0.009 – 0.136) suggesting that reciprocity mediates the relationship between apathy severity and burnout. Against our predictions, no significant effects were found between the a, b or ab path for any other mediator.

The effect between apathy severity and burnout whilst accounting for both direct and indirect effects and after bootstrapping remained significant (c - β =0.028, bootstrapped CI =0.008 – 0.048).

2.5.3 Differences in Burnout between groups Analysis of potential differences in burnout levels (OLBI-FS) dependent on the different demographic characteristics of respondent, highlighted significant differences (see **Table 2.5**). Respondents who spoke English as their first language had significantly lower rates of burnout (*F*(72) = 9.51, *p* <0.01) than those who did not speak English as their first language, however only 6% of the sample indicated English was not their first language. There was a significant difference between burnout and educational attainment (*F*(71) = 3.23, *p* = 0.03). Tukey's HSD comparisons showed that this was due to respondents with postgraduate level qualifications reporting higher levels of burnout than respondents with college level qualifications (*p* = 0.03). Significant differences were also indicated between respondents perceptions of how appropriate staffing levels were and their level of burnout (*F*(71) = 6.84, *p*<0.001). These differences were between those who reported staffing levels were "never" appropriate versus appropriate "all of the time" (*p* < 0.01); appropriate "some of the time" versus "all of the time" (*p* = 0.01); appropriate "never" versus “most of the time” ($p = 0.01$); and, appropriate “some of the time” versus “most of the time” ($p = 0.05$). Burnout levels were also significantly different in relation to staff’s perceptions of whether they had enough time to attend to both their own and their resident's needs ($F(71) = 7.96$, $p < 0.001$). Significant differences were between those who report psychological needs were “never” met versus met “all of the time” ($p = 0.01$); met “some of the time” versus “all of the time” ($p = 0.04$); met “never” versus “most of the time” ($p < 0.01$); and, met “some of the time” versus “most of the time” ($p < 0.01$).

Table 2.5. Differences in burnout levels (OLBI-FS) depending on demographic groupings.

Demographic Variable (*N*)	**OLBI-FS**			
	M	**SD**	**F statistic, *p*,**	**η_p^2**
Job Role (*n* = 75)	-	-	2.34, 0.06,	0.12
Care Assistant	2.44	0.39	-	
Senior Care Assistant	2.21	0.49	-	
Nurse	2.72	0.77	-	
Senior Nurse	2.43	0.32	-	
Manager/Deputy Manager	2.55	0.31	-	
Gender (*n* = 75)	-	-	0.95, 0.40	0.03
Male	2.16	0.46	-	
Female	2.42	0.46	-	
Not Specified	2.44	NA	-	
English First Language (*n* = 74)	-	-	9.51, **< 0.01****	0.12
Yes	2.36	0.45	-	
No	2.99	0.33	-	
Educational Attainment (*n* = 75)	-	-	3.23, **0.03***	0.12
Secondary	2.33	0.44	-	
College	2.29	0.42	-	
Undergraduate	2.56	0.40	-	
Postgraduate	2.73	0.56	-	
Hours Worked in Relation to Contracted (*n* = 73)	-	-	0.09, 0.92	0.003
Under	2.49	0.29	-	
Equivalent	2.40	0.49	-	
Over	2.39	0.48	-	

Staffing Level Appropriateness (*n* = 75)	-	-	6.84, **< 0.001****	0.22
Never	2.26	0.45	-	
Some of the time	2.48	0.41	-	
Most of the time	2.76	0.41	-	
All of the time	3.17	0.46	-	
Sufficient time for Staff's Psychological Needs? (*n* = 75)	-	-	7.96, **< 0.001*****	0.25
Never	2.79	0.43	-	
Some of the Time	2.52	0.37	-	
Most of the Time	2.14	0.46	-	
All of the Time	1.85	0.56	-	
Contact With Stress & Distress Team (*n* = 75)	-	-	0.01, 0.99	<0.001
Yes	2.40	0.51	-	
No	2.40	0.37	-	
Don't Know	2.41	0.46	-	
Training – Essentials and/or Stress & Distress (*n* = 75)	-	-	0.40, 0.67	0.02
None	2.37	0.44	-	
One	2.45	0.42	-	
Both	2.31	0.88	-	

n is used to indicate available sample sizes for each group tested. Total sample =82. Total available sample with burnout level data = 75. $^{*}p$ </=0.05, $^{**}p$ </=0.01, $^{***}p$ </=0.001. OLBI-FS = Oldenberg Burnout Inventory full scale

2.5.4 Associations with Burnout

Correlations between burnout and continuous demographic variables revealed no significant associations (see **Table B3.1**).

2.6 Discussion

In the present study we found that care staff's ratings of the severity of the apathy in the PWD in their care, were associated with their own experience of burnout; the more severe the apathy, the more burnout they felt (β = 0.268; 95% CI =0.003 – 0.043). Furthermore, there is some preliminary evidence that this relationship may be mediated by perceived reciprocity between care staff and the residents in their care (β = 0.054; 95% bootstrapped CI = 0.009 – 0.136), but there is no evidence that the other measured attributions (empathy, controllability, and self-efficacy) mediate this relationship within the current sample.

Higher levels of apathy in PWD (as rated by staff) were linked to higher levels of burnout in formal dementia caregivers. Although it has been well-evidenced that apathy is highly prevalent in PWD and that this can be associated with higher caregiver burden (e.g., Rajkumar et al., 2016), this is the first study, to our knowledge, that has assessed and evidenced the apathy-burnout relationship in this setting; previous studies have focused on the adverse impact of aggressive/agitated behaviours on staff wellbeing (Denning et al., 2021). The current finding offers further support for the need for further research on the impacts of apathy on dementia/dementia care (Dening et al., 2021), as well as the implementation of interventions targeting apathy within residential care (Cai et al., 2020; Boersma et al., 2015). Provision of these interventions may not only lead to reductions in apathy and better prognosis for the PWD but may also improve staff wellbeing (Isik et al., 2019). However, due to the low response rates for the current study and the associated potential lack of power and generalisability of these findings, all results must be interpreted with caution and require replication.

We also found evidence that staff’s attributions of reciprocity of the carer-resident relationship may mediate the association between apathy severity and staff burnout. This result indicates a potential intervention pathway; modifying the relationships (or at least the perceptions thereof) between carers and the PWD in their care, may reduce experiences of burnout in staff. However, research into reciprocity and its association with care staff wellbeing within the dementia population has been limited in recent years (most studies conducted 2005-2010), suggesting more research is needed to fully understand this relationship. Models, such as the dual-level social exchange model for burnout (Schaufeli et al., 1996), offers a theoretical framework that may facilitate understanding of this relationship as well as support the development of interventions that can be implemented within dementia settings.

Due to the measure for reciprocity used within the current analysis, it is not possible to determine in which way the carer-resident relationship was imbalanced; only that a higher imbalance is related to higher levels of staff burnout. However, non-transformed scores of reciprocity suggest that, on average, staff perceive that they put more into this exchange than they receive from the residents. This is consistent with previous studies (Duffy et al., 2009; Mills & Rose., 2011; Rose et al., 2010) and traditional organisational structures whereby care staff are often required to lead the carer-resident relationship (particularly in dyads containing more severe dementia), in order to provide a good level of care (Helleberg & Hauge, 2014). For these same reasons, relationship improvement interventions should be focused on providing staff with education and support for greater impact. Furthermore, having supports in place to help staff manage any feelings of frustration that may accompany this perceived imbalance (e.g., Baber et al., 2021) could also be beneficial. Future studies should examine the development/adaptation and implementation of non-pharmacological interventions that target reciprocity and assess their impact on both apathy severity in PWD and burnout in staff.

None of the other assessed attributions (self-efficacy, empathy, and controllability) were found to mediate the relationship between apathy severity and burnout, nor did they show any relationship with apathy and/or burnout individually. Lack of an effect for empathy and controllability as mediators was not unexpected as, in line with the original power estimates for this study (**see** **OSF Protocol**), the current sample was underpowered (recommended *n* = 82 and 370 for regression and mediation, respectively). Nevertheless, as these factors had not been previously assessed as mediators for apathy and burnout in dementia samples, further investigation was believed warranted. However, the resulting effect sizes for associations between burnout and both empathy (*r* = 0.03) and controllability (*r* = 0.01) in the current analyses were much smaller than those used in the power estimate (*r* = 0.24 and 0.21, respectively, see **Table B3.2**). Therefore, although the use of bootstrapping in the mediation analysis may have allowed us to generate a more normally distributed sample as well as reasonable estimates of a larger sample to test our hypotheses (Wood, 2005); replication in much larger, representative samples are required to determine if these effects, and the subsequent mediations exist in the formal dementia carer populations.

The lack of an effect between self-efficacy and burnout was unexpected, given previous findings of higher self-efficacy being associated with lower staff burnout in dementia care settings; residential (Duffy et al., 2009) and ward (Zhang et al., 2014). Furthermore, *a priori* and *ad hoc* power calculations (Gpower, v3.1.9.4; Faul et al., 2009) indicated that the current sample should be able to detect this effect (see **Table B3.2**). It is possible that the use of a single item measure as opposed to standardised questionnaires (e.g., Inventory of Geriatric Nursing Self-Efficacy; Mackenzie and Peragine, 2003, previously used in Duffy et al., 2009) impeded our ability to find this effect. However, single-item measures of self-efficacy have previously been evidenced to be reliable when compared to multiple-item measures, and have the added benefit of reducing time pressures (Hoeppner et al., 2011); an important consideration within the dementia care field.

It is also possible that the relationship between the measured factors is more complex than the current analysis can assess. For example, previous studies have linked other variables such as resilience, personality style, coping strategies with caregiver burden, and personal wellbeing (Wong et al., 2020, Baharudin et al., 2019, Lautenschlager et al., 2013); with one study identifying coping strategies and personality traits as potential mediators between DB and caregiver burden in informal carers (Baharudin et al., 2019). Furthermore, the current study found significant associations between burnout and several staff/job characteristics; staff who spoke English as their first language, had higher levels of educational attainment, perceived staffing levels to be lower than appropriate, and had less time to focus on the psychological needs of themselves and their residents, were all linked with higher levels of burnout. Thus, it may be that it is an accumulation of risk factors that elevate burnout risk and therefore, the apathy-burnout (or even the apathy-burnout mediated by reciprocity) pathways alone are not enough to explain the variance in burnout responses.

Moreover, in line with the findings from the limited number of studies available as well as the limited power in the current study, we only assessed the potential mediating (causal) effects of staff attribution variables on the apathy-dementia relationship. However, it is possible that these variables may act as moderators, influencing the strength of the relationship between apathy and burnout. For example, Zhang et al. (2014) noted that the relationship between BPSD (DB) and the caregivers perceived level of burden was dependent on the level of self-efficacy the caregiver had thus, self-efficacy may also act as a moderator between apathy severity in residents with dementia and the level of burnout in staff. Further studies using statistical methods such as structural equation modelling (SEM) may be required to fully assess the possible interactions between staff attributions (including mediating and moderating pathways), demographics, and contextual factors of the care setting on the apathy-burnout relationship.

In addition, we did not assess the severity of other types of DB present in residents within the care staff’s care. The current respondents indicated that an average of 36% of residents in their care present with aggression. As behaviours such as aggression, delusions, and depression are also highly prevalent and can be co-occurring (Cerejeira et al., 2012, Rajkumar et al., 2016), it is possible that staff’s experience of these DBs in the same or other residents is also influencing their level of burnout. Future studies should also control for the impact of these other behaviours within the multivariate apathy-burnout relationship.

Within the current sample the proportion of people who experienced burnout was high; 88%. Another recent survey reported burnout rates of 79% in healthcare workers, predominantly in Scotland (Ferry et al., 2021). COVID-19 has had a number of adverse effects on care staff and their subsequent levels of burnout (Ferry et al., 2021). These samples were recruited within different stages of the COVID-19 pandemic (2020 for Ferry et al., 2021, versus 2022 for the current sample) and may have resulted in qualitatively and quantitatively different experiences of burnout. Furthermore, the response rate of the current survey was much lower than reported in previous studies despite extension of the original data collection window (8% compared to 75% (Costello et al., 2019a), for example), and were restricted to NHS Highland staff; suggesting that this sample may not be representative of the general population. These results therefore require replication and future studies may benefit from considering potential variations in the impact of COVID-19 on burnout.

2.6.1 Limitations

There were several limitations with this study. Small sample size, due to low survey response rates, meant the study was underpowered (considering initial required sample size estimates), and external validity of the sample is likely confined to care home settings in the NHS Highland catchment. Therefore, results need to be interpreted with caution and replication in larger samples is required.

Some potential limitations were also identified in relation to the measures used; the measure of reciprocity doesn't allow for exploration of the direction of the reciprocity imbalance in linear analysis models, and the self-efficacy measure was a single item.

Development of reciprocity measures and inclusion of self-efficacy measures with more rigour, may be needed. Additionally, as higher levels of burnout can mean greater disconnection between staff and their work (Delgadillo et al., 2018), and a self-report survey methodology was used in the current study, it is also possible that the higher rates of burnout experienced in the current sample resulted in staff overestimating the levels of apathy in the PWD they care for. Future studies may therefore benefit from using corroborative measures of apathy however, accurate and holistic measures of this construct are reportedly lacking in the literature base (Dening et al., 2021; Mast et al., 2022).

Finally, the current methodology does not allow for exploration of the complexity of the relationship between apathy and burnout; experimental studies with enough power to implement SEM models which can assess moderating and mediating effects of the staff, patient, and contextual factors of apathy in dementia are required.

2.6.2 Conclusions

The current study found evidence that more severe levels of apathy in PWD in residential care are related to higher levels of burnout in staff. This finding, together with the high prevalence of apathy evidenced in the literature (Rajkumar et al., 2016), suggest that further research is needed to fully explore the impact of apathy on PWD and their carers (Dening et al., 2021). Additionally, more resources dedicated to apathy may need to be incorporated into staff wellbeing and educational interventions in order to better support their ability to care for PWD and meet their own needs (Dening et al., 2021). Efforts to adapt and implement existing interventions, with evidenced effectiveness for relieving symptoms of apathy within residential care settings (e.g., Cai et al., 2020, Boersma et al., 2015), will also be required.

Furthermore, we found evidence of potential mediation of the relationship between apathy and burnout by perceived imbalance in the relationship between carers and the PWD they care for. Due to inherent power imbalances within the carer-cared for relationships, and vulnerabilities in PWD that will make it difficult for them to adapt their level of need (Helleberg & Hauge, 2014); development/implementation of interventions targeted at supporting staff to manage this relationship (and the emotional impact it may have on them) would also be beneficial. Further research is needed to replicate the current findings in larger, more representative residential care samples.

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Appendices

Appendix A1 – Systematic Review Search Strategy (MEDLINE)

MEDLINE (EBSCO) SEARCH: Last run 01/06/22

Line	Search Term	Results
S56	S52 AND S53 AND S54 AND S55	(2,460)
S55	S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51	(2,212,590)
S54	S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43	(1,053,886)
S53	S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27	(289,251)
S52	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17	(894,303)
S51	(MH "Institutionalization")	(5,477)
S50	(MH "Long-Term Care")	(27,656)
S49	(MH "Skilled Nursing Facilities")	(4,985)
S48	(MH "Nursing Homes")	(37,971)
S47	(MH "Homes for the Aged")	(14,607)
S46	(MH "Residential Facilities")	(5,698)
S45	(nurs* OR residential OR long#term OR long#stay OR LTC OR daily OR "24#hour" OR institution* OR formal OR skill* OR special* OR elder* OR dementia OR "old* people*" OR "old* person*" OR "old* adult*" OR aged OR geriatric OR psychogeriatric OR assist*) N4 (home OR facilit* OR setting* OR provider* OR ward* OR living)	(1,108,754)
S44	(extended OR long#term OR long#stay OR daily OR "24#hour" OR residential OR institution* OR nurs* OR formal OR skill* OR special* OR elder* OR dementia OR "old* people*" OR "old* person*" OR "old* adult*" OR aged OR geriatric OR assist*) N1 care	(1,585,621)
S43	(MH "Apathy")	(1,481)
S42	AB ((reduc* OR chang* OR habitual OR daily) N2 activ*) OR TI ((reduc* OR chang* OR habitual OR daily) N2 activ*)	(282,147)
S41	AB (shadowing or vocali#ing or "calling out" or repetitive* or wandering or disinhibition*) OR TI (shadowing or vocali#ing or "calling out" or repetitive* or wandering or disinhibition*)	(94,350)
S40	AB ((disorder* or disturb* or difficult* or reduc* or poor*) N2 sleep*) OR TI ((disorder* or disturb* or difficult* or reduc* or poor*) N2 sleep*)	(61,474)
S39	AB ("*social *engage*" OR sociali* OR sociable OR "socia* interaction*" OR anti#social) OR TI ("*social *engage*" OR sociali* OR sociable OR "socia* interaction*" OR anti#social)	(51,744)
S38	AB ((chang* OR improv* OR reduc*) N2 mood) OR TI ((chang* OR improv* OR reduc*) N2 mood)	(8,975)

S37	AB (anxiety OR anxieties OR anxious) OR TI (anxiety OR anxieties OR anxious)	(238,321)
S36	AB (irritabil* OR labil*) OR TI (irritabil* OR labil*)	(47,823)
S35	AB ((positive OR negative OR chang*) N2 attitude*) OR TI ((positive OR negative OR chang*) N2 attitude*)	(30,780)
S34	AB (aggress* OR agitat*) OR TI (aggress* OR agitat*)	(253,748)
S33	AB (apath*) OR TI (apath*)	(7,093)
S32	AB ("disruptive behavio#r*" OR "maladapt* behavio#r*" OR "distress* behavio#r*" OR "stress reaction*" OR "need#driven" OR"responsive behavio#r*") OR TI ("disruptive behavio#r*" OR "maladapt* behavio#r*" OR "distress* behavio#r*" OR "stress reaction*" OR "need#driven" OR"responsive behavio#r*")	(10,835)
S31	AB ("non#cognitive symptom*") OR TI ("non#cognitive symptom*")	(96)
S30	AB ("behavio#r* disturbance*" OR "behavio#r* symptom*") OR TI ("behavio#r* disturbance*" OR "behavio#r* symptom*")	(9,554)
S29	AB ("neuro#psychiatric symptom*" OR "psychological and behavio#ral symptom*" OR "psycho-behavio#ral symptom*" OR "psycho behavio#ral symptom*" OR "psychobehavio#ral symptom*" OR "psychiatric symptom*" OR "psychological symptom*") OR TI ("neuro#psychiatric symptom*" OR "psychological and behavio#ral symptom*" OR "psycho-behavio#ral symptom*" OR "psycho behavio#ral symptom*" OR "psychobehavio#ral symptom*" OR "psychiatric symptom*" OR "psychological symptom*")	(26,997)
S28	AB ("behavio#ral and psychological symptom* of dementia" OR BPSD) OR TI ("behavio#ral and psychological symptom* of dementia" OR BPSD)	(1,768)
S27	(MH "Alzheimer's Disease")	(154,205)
S26	(MH "Dementia")	(57,997)
S25	AB (creutzfeldt or "creutzfeldt#jakob disease" or jcd or cjd) OR TI (creutzfeldt or "creutzfeldt#jakob disease" or jcd or cjd)	(7,271)
S24	AB (pick* N2 disease) OR TI (pick* N2 disease)	(4,025)
S23	AB (cerebr* N2 (deteriorat* OR insufficien*)) OR TI (cerebr* N2 (deteriorat* OR insufficien*))	(2,612)
S22	AB ("benign senescent forgetfulness") OR TI ("benign senescent forgetfulness")	(18)
S21	AB ("organic brain disease" or "organic brain syndrome") OR TI ("organic brain disease" or "organic brain syndrome")	(799)
S20	AB (chronic N2 cerebrovascular) OR TI (chronic N2 cerebrovascular)	(1,056)
S19	AB (lewy* N2 bod*) OR TI (lewy* N2 bod*)	(10,587)
S18	AB (dement* OR alzheimer* OR delirium) OR TI (dement* OR alzheimer* OR delirium)	(263,834)
S17	(MH "Guideline Adherence+")	(34,687)
S16	(MH "Diffusion of Innovation+")	(21,231)
S15	AB ((tailor* or adapt*) N2 content) OR TI ((tailor* or adapt*) N2 content)	(1,501)

S14	AB ((stud* OR therap* OR evidence* OR method* OR research* OR practice* OR program* OR project* OR care OR protocol* OR train*) N6 implement*) OR TI ((stud* OR therap* OR evidence* OR method* OR research OR practice* OR program* OR project OR care OR protocol* OR train*) N6 implement*)	(222,438)
S13	AB ((chang* or improv*) N2 (practic* or behavio#r* or intervention*)) OR TI ((chang* or improv*) N2 (practic* or behavio#r* or intervention*))	(136,710)
S12	AB ((adher* or enforc* or implement* or impact* or uptak* or follow*) N3 guideline*) OR TI ((adher* or enforc* or implement* or impact* or uptak* or follow*) N3 guideline*)	(43,317)
S11	AB ("academic* detailing" OR "patient#mediated" OR "communit* of practice" OR "opinion leader*" OR "best practice*" OR "organi#ational change*" OR "barrier* and facilitator*" OR "barrier* or facilitator*") OR TI ("academic* detailing" OR "patient#mediated" OR "communit* of practice" OR "opinion leader*" OR "best practice*" OR "organi#ational change*" OR "barrier* and facilitator*" OR "barrier* or facilitator*")	(47,793)
S10	AB ((knowledge or evidence* or practice*) N2 (gap* or barrier*)) OR TI ((knowledge or evidence* or practice*) N2 (gap* or barrier*))	(41,733)
S9	AB ((continu* or group* or outreach or plan* or practitioner* or program* or staff* or team*) N3 education*) OR TI ((continu* or group* or outreach or plan* or practitioner* or program* or staff* or team*) N3 education*)	(111,678)
S8	AB ((knowledge or evidence* or qualit* or research* or practice*) N2 gap*) OR TI ((knowledge or evidence* or qualit* or research* or practice*) N2 gap*)	(44,797)
S7	AB ("process evaluation*") OR TI ("process evaluation*")	(4,667)
S6	AB ("research findings into action" or "research to action" or "research into action" or "evidence to action" or "evidence to practice" or "evidence into practice") OR TI ("research findings into action" or "research to action" or "research into action" or "evidence to action" or "evidence to practice" or "evidence into practice")	(1,467)
S5	AB ((adoption* or diffus* or disseminat* or exchang* or transfer* or translation* or application* or implement* or mobil* or transfer* or uptak* or utili*) N2 research*) OR TI ((adoption* or diffus* or disseminat* or exchang* or transfer* or translation* or application* or implement* or mobil* or transfer* or uptak* or utili*) N2 research*)	(60,436)
S4	AB ((application* or broke* or diffus* or disseminat* or decision* or exchang* or implement* or interven* or mobili* or plan* or policy or policies or strateg* or translat* or transfer* or uptak* or utili*) N2 ("knowledge translation" OR "KT")) OR TI ((application* or broke* or diffus* or disseminat* or decision* or exchang* or implement* or interven* or mobili* or plan* or policy or policies or strateg* or translat* or	(3,581)

	transfer* or uptak* or utili*) N2 ("knowledge translation" OR "KT"))	
S3	AB ((adher* or adoption* or exchang* or translat* or transfer* or diffus* or disseminat* or exchang* or implement* or manage* or mobil* or uptak* or utili* or program*) N2(3) evidence* OR intervention*) OR TI ((adher* or adoption* or exchang* or translat* or transfer* or diffus* or disseminat* or exchang* or implement* or manage* or mobil* or uptak* or utili*) N2 evidence*)	(34,040)
S2	AB ((transmission* or application* or broke* or creation* or diffus* or disseminat* or exchang* or implement* or manage* or mobili*or translat* or transfer* or uptak* or utili*) N3 knowledge) OR TI ((transmission* or application* or broke* or creation* or diffus* or disseminat* or exchang* or implement* or manage* or mobili*or translat* or transfer* or uptak* or utili*) N3 knowledge)	(32,258)
S1	AB ((adher* or adoption* or implement* or manage* or uptak* or utili* or tailor* or adapt* or effectiv*) N3 car*) or TI ((adher* or adoption* or implement* or manage* or uptak* or utili* or tailor* or adapt* or effectiv*) N3 car*)	(251,214)

Words in red indicate suggested changes as noted in the section below.

Follow the following links for all other search strategies used: CINAHL, PsycINFO, EMBASE, Cochrane

Of the five articles that were not identified by the search strategy, two may have been captured with slight adaptations to the initial strategy (these suggested changes can be found in the search strategy above, highlighted in red; Hsu et al., 2015 - line 3; Sánchez et al., 2016 – line 13). However, without re-running the search it is difficult to determine whether this would be an optimal strategy. The remaining three papers appeared to be so vague or lacking in key words in relation to process evaluation that it is likely that they would have been difficult to identify in a search strategy even with adaptations (Tang et al., 2018; Valenti Soler et al., 2015; Tappen & Williams, 2009).

Appendix B1 – Study Documentation Available on the OSFHome Platform

Follow the link **here** for a copy of the approved MRP Proposal/Protocol

Follow the link **here** for a copy of the Participant Information Sheet

Follow the link **here** for a copy of the full research survey used for the study

Appendix B3 – Supplementary Results

Table B3.1 Correlations between burnout (OLBI-FS) and continuous demographic variables

Variable	OLBI-FS	
	r	*p*
Age (*n*=71)	0.04	0.72
Years Worked in Current Post (*n*=75)	-0.04	0.73
Years Worked with PWD (*n*=75)	-0.11	0.36
Hours Worked this Week (*n*=73)	0.04	0.74
Hours Access to Activity-Coordinator (*n*=74)	0.2	0.09
Average Hours Sleep this Week (*n*=74)	0.18	0.12

Table showing correlations between demographic variables (potential confounds) and the outcome variable (burnout: OLBI-FS = Oldenberg Burnout Inventory full scale).

Table B3.2 Power calculations and effect sizes for associations between independent, dependent and mediator variables.

Association	*A Priori Power Analysis*		Current Effect Sizes		*Adhoc Power Analysis*	
	r **From Literature**	***n*** **required**	**Beta (β) - standardised**	**Converted *r***	**Power**	***n*** **Required**
a_4 = Apathy - Self-efficacy	-	-	0.05	0.10	-	-
a_3 = Apathy – Empathy	-	-	-0.05	-0.05	-	-
a_2 = Apathy – Reciprocity	-	-	0.23	0.28	-	-
a_1 = Apathy – Controllability	0.17	82	0.01	0.06	-	-
b_4 = Self-efficacy - Burnout	0.53	52	-0.14	-0.14	0.99	34
b_3 = Empathy – Burnout	0.24	60	0.03	0.08	0.06	204
b_2 = Reciprocity – Burnout	0.22	65	0.23	0.28	0.05	244
b_1 = Controllability - Burnout	0.21	67	0.01	0.06	0.99	36

Table showing the original *r* from the literature used to calculate power estimates and the minimum number of participants required (*n*) for power = 0.8, the standardised β coefficients for the associations tested between the mediators and the IV and DV in the current study, the current β coefficients converted into *r*, the observed power in the current sample and estimated samples needed to detect an effect (power =0.8) using the current effect sizes. Power calculated using Gpower, v3.1.9.4; Faul et al., 2009.

Beta coefficients were converted to *r* using the Peterson and Brown (2005) method. Calculator available at https://www.psychometrica.de/effect_size.html using the 'Imputation from standardized Beta weights from multiple regression analysis' option.