Lost in translation? Exploring the usefulness of three methods to identify best sources of evidence for care staff on the non-pharmacological alleviation of Responsive behaviours in dementia

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Lost in translation? Exploring the usefulness of three methods to identify best sources of evidence for care staff on the non-pharmacological alleviation of Responsive behaviours in dementia

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School of Nursing

May, 2020
Abstract

Healthcare providers are faced with many challenges when trying to meet the complex needs of those with age related diseases, such as dementia. In residential aged care facilities (RACFs), up to 90% of those with dementia exhibit responsive behaviours (RB) and these are associated with increases in mortality, morbidity and decreased quality-of-life for residents. The term ‘responsive behaviours’ refers to words and actions displayed in response to personal, social or physical environments and are an expression of meaning, needs or concerns.

There is a need for more focus in policy, practice and research to improve the management of and reduce the negative impacts of RB on residents and care staff within RACFs. Affective RB symptoms in particular have been found to be the most burdensome. In time constrained workplaces, care staff require guidance towards resources that can facilitate better evidence based practice (EBP). This research adopts the Outcome-Focused Knowledge Translation Framework (OFKTF) in its investigation of knowledge translation (KT) with the aim of identifying best ‘sources of evidence’ to inform practices which are useful to care staff to support residents with affective RB. Specifically, the series of studies undertaken investigates the value of different approaches to synthesis and identifying best ‘sources of evidence’ to guide knowledge translation. Study 1 utilises panoramic meta-analysis (a statistical method pooling effect estimates over systematic reviews and meta-analyses, similar to a systematic review of systematic reviews and meta-analyses) to synthesise the available literature on non-pharmacological interventions for affective RB. However this method was unable to generate definitive recommendations for the non-pharmacological intervention of affective symptoms. This is due to heterogeneity and sampling issues within the included RCTs and insufficient number of RCTs to generate power within the calculations. Despite this, the review highlights overall positive outcomes from the use of non-pharmacological interventions for affective symptoms. It is also useful to generate three tentative recommendations regarding the best available interventions for practice: music therapy for anxiety, staff development for depression and person-centred care for aggression. Despite some value, the study concludes that EB management of RBs in RACFs would also benefit from alternative sources of evidence including expert opinion and an assessment of the quality and useability of CPGs.
To address this, Study 2 identifies available clinical guidelines using a systematic search and assesses their quality using the Intervention Centre for Allied Health Evidence (iCAHE) guideline quality checklist. Two of seven identified CPGs reach a high level of quality. Despite being ranked second, The Behaviour Management: A Guide to good Practice (DBMAS) guide is judged to be the clearest, most complete and easiest to navigate CPG. Quality assessment is found to be insufficient in isolation to identify best sources of evidence but has promise when used in conjunction with other methods such as clinical expertise.

Following on from this, Study 3 sought to establish expert opinion regarding best available guidelines for management of RB. This is achieved through surveying a panel of experts on their use and recommendation of different CPGs. Results from this study highlight the Behaviour Management: A Guide to good Practice (DBMAS) as a high quality guideline with expert preference. Expert preference for guidelines was the same for both overall management of RBs and specifically for the management of affective symptoms. The survey method is able to generate clearer recommendations for RB interventions by comparing quality assessment with expert opinion to reveal the Behaviour Management: A Guide to good Practice (DBMAS) as a high-quality CPG with expert recommendation. However, the results should be interpreted with caution, due to the small and potentially biased sample for the study. The additional value of expert opinion (study 3) to identify best sources of evidence is less conclusive due to study bias. However, overall, the value of mixed methods approaches when identifying ‘sources of evidence’ for KT, should be promoted, especially where the quality of evidence is low.

The studies undertaken highlight that the different methods (research synthesis (study 1) and analysis of quality and usability of guidelines (study 2)) are useful to assist in identifying best ‘sources of evidence’ for non-pharmacological alleviation of affective responsive behaviours in dementia.
Acknowledgments

Firstly, I would like to thank my supervisors: Professor Richard Fleming and Dr Lyn Phillipson. Without their unwavering support, patience and efforts I would not have reached the completion of this thesis. Their encouragement throughout my research process and struggle with health issues has been exceptional. They have continued to inspire me with their diligence and enthusiasm towards quality research to advance dementia care standards in healthcare.

Words cannot express my utmost gratitude to all my family and friends who have been by my side throughout my studies. This is especially so for my husband and best friend, Mateusz. Without you by my side I could not have dreamed of getting here. You have been my rock when times were hard and gave me the strength to face each battle. To my dearest mother, your unwavering support and zest for life inspire me every day and will continue to do so heading into my next adventure of ‘motherhood’.

This thesis has been partially funded by the Rotary Club of West Wollongong, Rotary Australia and the University of Wollongong. As such I would like to thank the staff involved, with special mention to Michael Crowley, President of Rotary Club of West Wollongong. Your enthusiasm for young researchers has given me the opportunity to reach my goals and make my mark on current dementia care practices.

Finally, I would like to thank the RACF care staff and DBMAS consultants who assisted in this research. Your daily efforts to assist those with dementia cannot be undervalued. I hope this research has helped build an environment where support is given to those who patiently care for residents with dementia on a daily basis.
Certification

I, Catherine Kubel, declare that this thesis submitted in fulfilment of the requirements for the conferral of the degree Master of Philosophy from the University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. This document has not been submitted for qualifications at any other academic institution.

____________________________

Catherine Kubel

May, 2020
## List of Names or Abbreviations

<table>
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<tr>
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<th>Full Form</th>
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<tbody>
<tr>
<td>CPG</td>
<td>Clinical Practice Guideline</td>
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<tr>
<td>RB</td>
<td>Responsive behaviour</td>
</tr>
<tr>
<td>BPSD</td>
<td>Behavioural and Psychological Symptoms of Dementia</td>
</tr>
<tr>
<td>KT</td>
<td>Knowledge Translation</td>
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<tr>
<td>OFKTF</td>
<td>Outcomes Focused Knowledge Translation Framework</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>EBP</td>
<td>Evidence Based Practice</td>
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<tr>
<td>PARIHS</td>
<td>Promoting Action on Research Implementation in Health Services Framework</td>
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<tr>
<td>NPI</td>
<td>Neuropsychiatric Inventory</td>
</tr>
<tr>
<td>CMAI</td>
<td>Cohen-Mansfield Agitation Inventory</td>
</tr>
<tr>
<td>CDS</td>
<td>Cornell Depression Scale</td>
</tr>
<tr>
<td>iCAHE</td>
<td>Intervention Centre for Allied Health Evidence</td>
</tr>
<tr>
<td>RACF</td>
<td>Residential Aged Care Facility</td>
</tr>
<tr>
<td>NRS</td>
<td>Non-Randomised Study</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Control Trial</td>
</tr>
<tr>
<td>AMSTAR</td>
<td>A Measurement Tool to Assess systematic Reviews</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>SPT</td>
<td>Simulated Presence Therapy</td>
</tr>
<tr>
<td>PCC</td>
<td>Person Centred Care</td>
</tr>
<tr>
<td>SMD</td>
<td>Standardized Mean Difference</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>M</td>
<td>Mean</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>DBMAS</td>
<td>Dementia Behaviour Management Advisory Scheme</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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Chapter 1 - Introduction

"NOW IS THE TIME TO MAKE IT HAPPEN WHERE IT MATTERS, BY TURNING SCIENTIFIC KNOWLEDGE INTO EFFECTIVE ACTION FOR PEOPLE’S HEALTH”

DIRECTOR-GENERAL OF THE WORLD HEALTH ORGANIZATION, DR J.W. LEE

Background

Medical discoveries and improvements in public health services have extended the human lifespan over the past decades and led to an increase in ageing populations, or what has come to be known as the “Grey Tsunami” [1]. In 2016, there were approximately 3.7 million people in Australia over the age of 65 [2]. This is estimated to reach 8.1 million by 2056 [3]. Hand in hand with this increased longevity is the increase in diseases with age as a primary risk factor, such as dementia. The prevalence of dementia is estimated to be doubling every 20 years and it is predicted that by 2050 there will be close to 1 million people with dementia in Australia and 135 million worldwide [4]. With this, a greater focus on the disease in policy, practice and research is not only necessary but is a critical health priority [1].

Those who develop dementia account for more than half the residents in supported residential accommodation [5]. Within these facilities, up to 90% of residents living with dementia experience Behavioural and Psychological Symptoms of Dementia (BPSD) and have associated increases in mortality, morbidity and decreased quality-of-life [6], [7] [8]. BPSD refers to the diversity of non-cognitive responses and behaviours in populations with dementia and includes symptoms such as agitation, depression, anxiety, apathy, delusions, hallucinations and sleep or appetite changes [8]. Although BPSD is the common term within the literature, it is now preferable to refer to these as ‘responsive behaviours’ (RB). This term was coined by, and preferred by [9], those with dementia to reflect that their words and actions are a response to their personal, social or physical environments and are an expression of meaning, needs or concerns [10]. For clarity, this term has been adopted within this research. These responsive behaviours can affect up to 90% of the those with a dementia diagnosis, regardless of subtype [8].
As dementia progresses the presentation of RB changes and it is useful to cluster symptoms to create sub-syndromes that reflect distinctive incidence, trajectories over time, biological correlates, and psychosocial determinants [11]. There are often co-morbidities and correlates in the causes and intervention of RB. In this research, clustering was necessary to limit the scope of research to manageable proportions and to focus the research on the most burdensome symptom cluster. The Neuropsychiatric Inventory (NPI) is the most commonly used and recommended assessment of RB within research and clinical realms and has been the main vehicle in the study of symptom taxonomy [12], [13]. While no consensus in regard to symptom grouping has yet been reached, the NPI derived symptom grouping set forth by Aalten and colleagues [14] is the most commonly used taxonomy within the literature. It divides symptoms into three classes; psychotic symptoms, affective/mood symptoms and behavioural symptoms [14]. Canevelli [15] systematically reviewed the literature on factor analysis of the NPI and found a 75% consensus for three clusters found within the 10-item NPI and a 57.1% consensus of four clusters within the 12-item version. The most frequent clusters were ‘psychosis (delusions, hallucinations and sleep and night time behaviour)’, ‘behavioural (elation/euphoria, disinhibition, appetite and aberrant motor behaviour)’, and mood/affective (depression/dysphoria, agitation/aggression, irritability and anxiety). These groups have been adopted in the current research given their high consensus within the literature.

The debate over cluster definition continues as there are symptoms (apathy, night-time behaviour and appetite behaviour) that are inconsistently placed throughout the literature [16]. Apathy is of concern in relation to affective/mood grouping. The distinction of apathy and depression is recognised by some [17], [18] but not by others [14]. It is, however, most commonly associated with the affective cluster when not classed as its own category and should be considered here for generalizability and ease of consensus. Given the evidence available on both most agreed upon clusters and most common placing of debatable symptoms (apathy, appetite, sleep) the following symptom taxonomy has been adopted in this research as the best available synthesis of current views. The affective cluster may be the most burdensome within the healthcare system as it encompasses the three most prevalent non-cognitive symptoms within dementia; apathy, depression and anxiety [11]. Given the scope of the RB literature, this Masters thesis adopted an affective symptom focus in its exploration of Sources of Evidence for the alleviation of RB in RACFs.
Table 1. Most consistent clustering of neuropsychiatric symptoms within the literature [17]

<table>
<thead>
<tr>
<th>Psychotic/Psychosis</th>
<th>Behaviour/hyperactive</th>
<th>Mood/affective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delusions</td>
<td>Euphoria/elation</td>
<td>Depression/dysphoria</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>Disinhibition</td>
<td>Agitation/aggression</td>
</tr>
<tr>
<td>Night-time behaviour</td>
<td>Eating/appetite behaviour</td>
<td>Irritability</td>
</tr>
<tr>
<td></td>
<td>Aberrant motor behaviour</td>
<td>Anxiety</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Apathy</td>
</tr>
</tbody>
</table>

The problem of responding appropriately to responsive behaviours

The presence of RB in persons with dementia is associated with earlier placement within care facilities, difficulty performing activities of daily living (ADL) [19], decreased cognitive ability, emotional regularity, functionality and insight [20]. Clinically, it reduces the likelihood of help-seeking behaviour, quality of life and survival rate after facility admission [21], [22].

RACF staff are significantly affected by RB presentation. Increased frequency of RB is correlated with reports of emotional strain and less positive work environments [23], declined physical health and work attendance and increased burnout [24]. In the absence of support for the application of non-pharmacological interventions, including time allocation with residents and to attend training, care staff often rely on chemical or physical restraints to manage RB [11], [25]–[27]. Estimates suggest that 84% of people with dementia living in RACFs are prescribed medication to relieve the symptoms of RB [28] and are often the first choice treatment strategies for nursing staff due to ease of administration and rapid effect. This is despite the fact that systematic reviews have found little evidence of the effectiveness of pharmacological treatments and increased problems with side effects such as stroke, cognitive decline and fatality [29], [30].

The level of care needed by residents in Australian aged care homes is increasingly complex. However, the ratio of registered nurses to care staff is reducing with more and more homes relying on having a registered nurse on call rather than on site [31]. Despite the need for skilled labour to improve EBP, up to
64% of care facility staff have been found to be care staff hired for cost-saving reasons [32]. Although this is improving, this population is still of particular interest and are a particular challenge as they often have additional barriers to attending training, such as having multiple jobs or not being reimbursed, despite being the most closely involved in the day-to-day care of residents when compared to registered nurses [33]. Care staff can be under trained in identifying the aetiology of problem behaviours, accessing quality resources or in selection of resources to assist decision-making and behaviour management [34]. In order to improve the care given by care staff, various factors need to be addressed [33]. These include support of decision making processes through ongoing support and the provision of easy-to-use research tools such as clinical practice guidelines (CPGs) [35].

CPG are defined as statements that include recommendations for EBP care that are usually informed by a systematic reviews and an assessment of alternative care options [36]. CPGs offer one option for assistance and supplementation of formal training for care staff in the evidence-based alleviation of RB. The aim of CPGs in RACFs is to “enhance research translation by synthesising recent evidence for health and aged care professionals” [37]. A number of guidelines for interventions for dementia have been developed yet there is little guidance available, or have expired, to help care staff select the most appropriate guideline [38]. The delivery of quality care requires that care staff are supported and educated in their decision making, yet it is unclear which guidelines facilitate the use of evidence in practice [11]. Care-staff can feel that taking time out from their work schedule to investigate current EBP is unethical as it takes time and focus from resident care [13]. Further, end users of CPGs have the expectation that resources will be of high quality and fit for purpose, yet guidelines have been found to be of varying quality[38]. Easily accessible high quality research evidence that is usable and understandable is needed. Research into the aetiology, treatment and care of RB is quite well established with promising results. Yet, it is practically inaccessible because care staff do not have the time, resources or skills to navigate large quantities of data to make evidence-based decisions. Further, design of guidelines needs to consider application within practical realms by care staff and must be assessed for quality to ensure they are promoting EBP. For example, a perceived lack of knowledge of academic processes and forms of communication have limited the applicability of research and CPGs must be translated into a user-friendly language [39]. Research reports and articles tend to be written for academic audiences, but they are unlikely to be usable within non-academic populations. Given this, the quality, selection of and usability of guidelines to support care staff in the alleviation of RB must be considered.
Knowledge Translation

As the proportion of Australians with a dementia diagnosis grows and the impact on those affected, their caregivers, healthcare systems, and the economy increases, the need to effectively translate research evidence into policy and practice becomes paramount. The primary objective of Knowledge Translation (KT) is to increase the tendency for care staff to utilise evidence-based research findings to inform health-care practices [39]. KT frameworks have the potential to guide research syntheses to generate clear recommendations for care and increase EBP. Knowledge Translation (KT) addresses the challenge of bridging the “know-do” gap [40]. It works from the premise that research has little value or legitimacy without being put into practice, being tested for clinical efficacy, and without being regularly evaluated. Translation of dementia related research has been determined to be a ‘Global Health Priority’ by the WHO [1] and a ‘National Priority’ by Australian governmental bodies [41]. Research evidence should underpin all action and reach those who can apply it to inform decisions [1]. In healthcare, KT has been defined as “the synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and improving people’s health” [42]. The following terms are overlapping and interrelated in the literature regarding knowledge translation; diffusion, dissemination, brokering, implementation, knowledge transfer, knowledge exchange, knowledge mobility, linkage and exchange, research into practice, research utilisation, evidence-based decision-making, knowledge uptake, research uptake, and research transfer [42]–[46]. In fact, there are over 90 terms for these processes [47]. Knowledge Translation (KT) is a process that encompasses the key concepts within many of these terms with the goal of ‘Evidence-Based Practice (EBP)’ and has been used within this document to describe the efforts leading to the uptake of evidence in practice. It is the most frequently accepted within the literature and has notions of practical utility with a focus beyond simple understanding through to action (e.g., decision-making [48]).

The core of KT is the need to translate results successfully, yet often attempts are unsuccessful. One explanation for this is the absence of theory-driven development of tools, intervention and assessment. Developing KT strategies based on theory allows for identification of focus (i.e., population specific tools), explanations (i.e., what works for whom and why) and generation of theoretically transferable knowledge [49]. KT strategies must be based on the best available evidence within literature supported frameworks.
Promoting Action on Research Implementation in Health Services (PARIHS) is a conceptual framework [50] which proposes that healthcare decision making relies upon the uptake of current best practice information, patient preferences and insight into patient responses [40]. The PARIHS framework allows for mixed-methods approaches, modelling research utilisation and assessing designs. Furthermore, the WHO report on KT frameworks identified the PARIHS as one of the few successful frameworks to work within clinical or organisational settings (rather than national or policy levels)[40]. The PARIHS follows a rationale that KT involves linking of research to action as a decision-making process or problem to be solved through problem identification, identification of research, and application of knowledge. Further the PAHRIS incorporates a “Successful Implementation (SI) Tool” which presents the notions that Successful Implementation (SI) is a function of Evidence (E), Context (C), and Facilitation (F), with Evidence being first line in approach.

\[ SI = function \ of \ E, \ C, \ F. \]

In response to the PARIHS framework, Doran and Sidani [51] set out to design an Outcome-Focused Knowledge Translation Framework (OFKTF) under the rationale that reconceptualising how care-staff “access information and designing appropriate decision support systems to facilitate timely designed focused on four key components adapted from the PARIHS framework and has advantage in directing research and practice towards avenues for EBP. The key components are as follows; 1) Sources of Evidence, such as clinical practice guidelines, research syntheses or local experience, fixed in decision support tools that relay key points in response to patient assessment data; 2) Facilitation, through leaders in the field with professional craft knowledge within individual and organisational parameters; 3) incorporation of Patient Preferences; and 4) Context, patient measurement, real-time feedback about intervention outcomes. The dynamics between these components are represented in Figure 1. These factors interplay to dictate the uptake of knowledge and the success of nursing interventions in improving patient outcomes. The research described in this thesis utilises the OFKTF Framework’s Sources of Evidence component in its examination of evidence-based RB management and clinical practice guidelines (CPGs). It was identified as the most appropriate for this research based on its grounding in the well-established PARIHS framework and its specific direction towards EBP and development of decision support systems in care.
The research reported in this Masters thesis focuses on the sources of evidence within the OFKTF as a starting point to quality care. Sources of Evidence within the framework include research syntheses, clinical practice guidelines, or experience and these have been the foundation of the exploration of KT to support non-pharmacological care of RB within this research. Research hierarchies place CPGs as first line for direct care and as such this thesis examined the strengths and weaknesses of CPGs to assist care staff to use non-pharmacological methods to alleviate Responsive behaviours in people with dementia. Nursing interventions work at the point of care to incorporate evidence into practice and to improve quality care. Nursing interventions have been found to directly mitigate symptomatic, functional, staff-based and economical outcomes. However, the term ‘nursing intervention’ as used within the OFKTF limits such approaches to nursing populations. The ratio of nurse to residents’ decreases and thus other carers such as care workers within RACFs need to be focus and as such, this thesis will direct its investigation of Sources of Evidence away from nursing populations towards care workers. It begins with an examination of the evidence base available for the development of guidelines, an evaluation of existing guidelines against an international standard is then reported followed by an evaluation of the utility of the most commonly used guidelines. Specifically, this thesis involves an investigation of methods of synthesis to compare available evidence (meta-synthesis) (Study 1), a rating of
the quality of currently available CPGs (Study 2) and investigation into expert recommendations of these guidelines (Study 3).

Research Question

This research aimed to address the question;

*In the context of Knowledge Translation, what is the usefulness of different methods to identify best ‘sources of evidence’ for care staff on the non-pharmacological alleviation of affective Responsive behaviours in dementia?*

Methods

A Sequential multiple methods approach was used to explore Sources of Evidence as a basis for KT. Specifically, it examined the utility of different methods to provide clear practice recommendations for the non-pharmacological intervention of affective RB in residential care facilities. The thesis describes three complementary studies:

Study 1 - *Assessing the utility of panoramic meta-analysis to guide recommendations for the non-pharmacological intervention of affective symptoms in dementia*

Study 1 responded to the vast amount of literature available to care staff and the need to syntheses this to promote EBP. Following a systematic search of available literature for the affective symptoms ‘cluster’ of behaviours dementia, the utility of panoramic meta-analysis to pool estimates across previous systematic reviews and meta-analyses and the ability of this synthesis method to identify best sources of evidence for care staff in practice were assessed.

Study 2- *Identification and Assessment of Quality in Clinical Practice Guidelines for Responsive behaviours*

Study 2 uses a systematic literature search to identify and assess currently available CPGs using the Intervention Centre for Allied Health Evidence (iCAHE) Guideline Quality Checklist to identify high ranking guidelines as
sources of evidence to support care staff in the alleviation of RB.

Study 3 - Expert recommendation of clinical practice guidelines and components that influence recommendation

Study 3 responded practically to the findings of Study 1 and 2. It argued that advanced methods of synthesis are currently unable to inform EBP and so practice must also rely on expert recommendation as a source of evidence to inform care. Study 3 used a survey method to explore the recommendations made by experts (Behaviour consultants from the Dementia Behaviour Management Advisory Service (DBMAS)) for CPGs and the reasons behind such recommendation for residential aged care staff to support RB and specified affective symptoms.
Chapter 2 - Assessing the utility of panoramic meta-analysis to guide recommendations for the non-pharmacological intervention of affective symptoms in dementia

Background

It is estimated that by 2050 there will be 135 million people living with dementia [54] prompting a critical need for improved diagnosis, treatment and management strategies to improve their quality of life [1]. Responsive behaviours (RB) affect over 90% of those with dementia [55] and have been identified as a primary burden on care staff within Residential Aged Care Facilities (RACFs) [56]. Mismanagement of RB within these facilities, such as the use of sedative pharmaceuticals or restraint, leads to poorer resident outcomes for those with dementia affecting mortality, morbidity and quality of life [7].

Due to the diverse range of symptoms encompassed within RB, there is a need for the establishment of sub-groups to reflect particular characteristics of the symptoms and their potential response to management strategies [11]. RB (or BPSD as they are commonly referred to in the literature) are most often divided into three groups; affective, behavioural and psychotic symptoms [57]–[59]. It is argued that affective symptoms are the most burdensome within the healthcare system as they encompass the three most prevalent non-cognitive symptoms of dementia; apathy, depression and anxiety [11], [60] as well as aggression and agitation. They are thus of primary concern in the pursuit of appropriate responses to RBs and form the focus of this review.

It has been estimated that 84% of people with dementia living in RACFs are prescribed medication to relieve symptoms [28] and medications are often the first choice treatment strategies for nursing staff due to ease of administration and rapid effect. This is despite the fact that systematic reviews have found little evidence of the effectiveness of pharmacological treatments but have identified increased problems with side effects such as stroke, cognitive decline and mortality [29], [30]. The serious problems being encountered with the use of
medications to alleviate responsive behaviours give rise to the need to review the current literature for non-
pharmacological interventions that will provide EBP alternatives to the use of medications. Given this, it is
necessary to review the current literature for non-pharmacological alternatives to promote the use of evidence
based strategies in care.

**Meta-analysis – A starting point for informing evidence based intervention for RB?**

Systematic reviews and meta-analyses aim to collate empirical research evidence and have been dubbed the
‘platinum standard of evidence’ [61] which sit atop the hierarchy for best evidence [52], [62]. Although
systematic reviews and meta-analyses sit atop evidence hierarches, they rely on narrow search criteria for
specificity and thus overarching insights into the scope of research evidence in a research domain cannot be
gained through a singular systematic review targeting one intervention or one symptom [63]. Systematic reviews
of systematic reviews offer a solution to synthesising this ever growing literature but fall short of quantifying the
evidence. A panoramic meta-analysis allows for pooling effect estimates over systematic reviews and meta-
analyses [64] and thus allows comparison of effectiveness for the abundance of interventions available for the
numerous presenting symptoms to generate clear recommendations. Given the diversity of research on the non-
pharmacological interventions for RB and the numerous reviews and meta-analyses, a panoramic review may be
an appropriate means for acquiring the best quantitative evidence to direct research and practice. A panoramic
methodology would be more suitable than alternative synthesis, such as systematic review of CPGs, due to its
ability to quantify comparisons of specific primary data to hone into specific symptoms or interventions, as
opposed to more collective clinical recommendations in CPG which reflect review conclusions which cannot be
segmented for specificity. It is this ability to segment into symptoms that allows for creation of tools like
the ‘matrix’ (p.26). This type of tool can easily be adapted to identify evidence-based strategies for
care workers. This type of methodology fits as a source of evidence by creating a more complete
picture of the evidence as a starting point for EBP and tools. However, this is adopted with
acknowledgement of limitation of this methodology such as overlap of primary studies, missing data not
included in reviews and the influence of primary study quality on heterogeneity. As the affective symptoms pose
the most critical problems within residential care settings [11], [60], [65] this review will utilise a panoramic
review to identify successful interventions by attempting to build a complete intervention by symptom matrix for the reduction of affective symptoms.

The specific review question to be addressed by this review is;

*Can panoramic methods identify best sources of evidence to support RACF staff regarding the non-pharmacological management of affective symptoms in residential aged care facilities?*

**Methods**

**Inclusion Criteria**

The Cochrane Collaboration [66] has recommended that meta-analyses “should not make any attempt to combine evidence from randomised trials (RCT) and non-randomised studies (NRS)” (13.2.1.1) as this may limit external validity [61]. However, the exclusion of NRS violates the notion of total evidence which attempts to gather all relevant information on a subject and limits the ability to judge a hypothesis as ‘informed’ [61]. This review aimed for the highest quality evidence level in accordance with the current guidelines and thus performed a meta-analysis of RCT studies only.

Thus, well-conducted systematic reviews of RCTs have been considered as level I research evidence for guideline development or other evidence appraisal. Meta-analyses that are not part of a systematic review or that refer to a set of RCTs might be considered level I or lower evidence, depending on the context. Systematic review and meta-analyses of observational data have been considered at the level of observational data and graded within this evidence level by the risk of bias in the analysis (compilation of adjusted or unadjusted analysis and other criteria) [61], [66].

**Systematic Search and Study Selection**

This review aimed to identify systematic reviews and meta-analyses published in English from 2005
to October, 2014 using the three phase JBI Methodology for Umbrella Reviews – Search Strategy (Section 2.6.5) [67]. Systematic searches of JBI SIRI, Scopus, Cochrane, PubMed, Medline, EMBASE, DARE, PROSPERO, Epistemonikos and CINAHL databases were conducted by one author (CK). Search strings included suitable indexing terms (i.e., MeSH terms and keywords) on (1) dementia (e.g., dementia; Alzheimer’s disease) and (2) BPSD (e.g., apathy, neuropsychiatric, affective) (see Appendix A for full search strategy).

**PICO**

This review adopted the Cochrane Collaboration suggested PICO framework (Participants, Interventions, Comparators, Outcomes) [66] in the development of research questions and inclusion criteria.

**Participants**

This review considered all studies that have a focus on those with a diagnosis of dementia living within Residential Aged Care Facilities (RACF). These facilities are often called nursing homes or assisted living facilities. It also considered studies in which those with dementia form part of a larger population but only when it was possible to extract data relating only to those with dementia.

**Intervention**

This review considered all research studies that specifically address non-pharmacological interventions for one or more affective symptoms of dementia.

**Comparators**

Included studies used control groups with “no treatment” or “care as usual” for matched participants.

**Outcome**

This review considered resident outcomes in regard to affective symptoms. These were primarily measured by the use of the Neuropsychiatric Inventory (NPI), Cohen-Mansfield Agitation Inventory (CMAI) and the Cornell Depression Scale (CDS). Articles were included if they were peer-reviewed meta-analyses or systematic reviews addressing the management of affective symptoms within residential aged care facilities. Titles and abstracts of identified articles were screened to determine inclusion eligibility. Title and abstracts were considered eligible for full text analysis if they made reference to one or more RB or non-pharmacological intervention. Full text versions of potential references were screened for final selection by one author (CK) to determine if PICO criteria was met. Additionally, reference lists of included reviews were examined manually to
Data Abstraction and methodological quality assessment

This review aimed to identify and include systematic reviews for the non-pharmacological management of affective symptoms which met a minimum standard of quality. To do this, the reviewers adopted the AMSTAR tool for reviewing quality of systematic reviews (Appendix B). The AMSTAR is a validated tool with high inter-rater agreement, reliability, construct validity, and feasibility that provides a means to assess systematic reviews for methodological quality [67]. Assessment of quality of systematic reviews was deemed more appropriate than assessment of individual RCTs included within reviews to limit the scope of the study and in reflection of high-quality reviews including RCT assessment within their data collection. Quality was adopted following the AMSTAR checklist terminology. This was done to remain consistent with included references. Two independent reviewers assessed the studies where the author (CK) assessed 100% of studies and supervisor (RF) assessed 20% to assess agreement. There was 100% consensus on the quality of studies.

Data were abstracted from systematic reviews and meta-analyses meeting inclusion criteria. Data abstracted included intervention type(s), study design, search methods, year published, number of included RCTs, use of data extraction methods, quality assessment, and inclusion of a meta-analysis. Primary study reports of identified RCT’s for non-pharmacological management of one or more affective symptom were identified from these reviews. Intervention type(s), year published, number of participants, before/after treatment means and standard deviations for control and experimental conditions and results from meta-analyses were abstracted from RCT reports.

Reviews were scanned manually by one author (CK) to identify primary RCT studies covered in two or more reviews or analyses. When identified, preference was given to reviews/meta-analyses according the following (ordered) criteria; reviews with RCT’s included within multiple analyses; availability of numerical data; inclusion of RCT’s only; recent publication date; larger numbers of studies and observations included.
Statistical analysis

Data were analysed using RevMan Review Manager 5.3 software and guidelines for meta-analyses obtained from the Cochrane Handbook for Systematic Reviews of Interventions [66]. Where Standard Deviations (SD) for change scores were not available within primary RCTs, calculations using correlation coefficients were performed. When available data did not allow for coefficient calculation, final SDs were used. Analyses included tests for effect size (Standardised Mean Difference) via a random effects model. SMD was adopted to allow comparison of various measures for the same outcome. A random-effects model was used under the assumption of exchangeability, and to account for the variance stemming from studies coming from various populations (see Section 10.10.4.4 Implementing random-effects meta-analyses [66]). Statistical heterogeneity was explored using the I-Squared statistic and interpreted using The Cochrane Collaboration’s guide to interpretation of $I^2$ [66]:

- 0% to 40%: might not be important
- 30% to 60%: may represent moderate heterogeneity
- 50% to 90%: may represent substantial heterogeneity
- 75% to 100%: considerable heterogeneity

Analyses were arranged by intervention type and outcome measure. For RCT’s reporting measures for global RBs or neuropsychiatric symptoms, such as the BEHAVE-AD, results were excluded from analyses. Evidence of publication bias was assessed using funnel plots and Egger’s regression.

Matrix Formation

This study developed a symptom by intervention comparison matrix in an attempt to generate clearer recommendations for care. This matrix adopted a shading system to visually represent levels of evidence for a specific combination. Where a study with a statistically significant result ($p<0.05$) had a large enough sample size ($N>300$), had sufficient data to perform systematic review ($N>4$) and had acceptable heterogeneity ($I^2<75\%$), it would be considered to have strong evidence. If only two of these conditions are met, a study would be considered to have moderate evidence. If only one of these conditions was met, it would be considered to have limited evidence.
Results

Search and study selection

The search identified 2037 potential reviews (Figure 1). After duplicates were removed, 1389 articles remained. Of these, 1262 were excluded after title and/or abstract screening revealed studies as non-systematic reviews, not in English, not focused on RB or non-pharmacological interventions and being community/home-based interventions. 127 full text articles were assessed for eligibility. Of these, following a complete reading of the text, a further 75 were excluded for the reasons stated above as well as reviews not including at least one RCT. 52 articles met eligibility criteria.

Quality Rating

In the interest of including only best evidence, articles meeting eligibility criteria underwent a quality assessment using the AMSTAR. A quality cut off point was set at a score of 7 out of 11 based on previous research identifying the Australian Government’s National Health and Medical Research Council typically supporting interventions that reached 65% of quality assessment [68]. Based on this, a further 23 review articles were excluded from the analysis.

Exclusions for Duplicate Primary Studies

9 reviews were excluded from the analysis due to duplication of primary studies included within articles[69]–[77].
Study Characteristics

The remaining 20 reviews are detailed in Table 2. Reviews were published between 2005 and 2014 and included a median of 4 (IQR 3-5, Mean=4.65) randomised control trials for non-pharmacological interventions for affective symptoms. The AMSTAR Score for systematic reviews and meta-analyses included within this review had a median of 8 (IQR 7-10, Mean=8.75).

Within reviews, 14 distinct intervention types were discovered. Categories were made based on terminology and
definition included in clinical practice guidelines or primary studies;

1) Music Therapy; engage the regular use of sounds, melodies and/or rhythmic movement provided through live music, singing or listening to cds or dvds [78]

2) Light Therapy – Sensory Intervention using varying sources of light to promote synchronization of circadian rhythms [79]

3) Therapeutic Touch; including acupressure and massage to promote relaxation [78]

4) Aromatherapy- Sensory Intervention using essential oils [70]

5) Activities Based Intervention – or Therapeutic recreation - a range of leisure activities that focus on improving daily functioning, independence and well-being. Examples include cooking activities, gardening or social interventions [78]

6) Exercise Based Intervention- some form of gentle to medium level physical activity such as walking and/or movement which targets balance, mobility, flexibility and/or strength [78]

7) Environmentally Based Intervention - dementia appropriate modifications to physical environments [78]

8) Multi-Sensory Stimulation (including Snoezelen) – Sensory Intervention through provision of unpatterned visual, auditory, olfactory, and tactile stimuli [80]

9) Behavioural/cognitive-behavioural interventions - based on behavioural theory (i.e. classical and operant conditioning) and/or cognitive theory (i.e. changing dysfunctional thinking) typically involving the active participation of carers [78]

10) Person Centred Care (PCC) and Provision for Unmet needs - specific care protocols or services that are implemented within RACFs [78]

11) Reminiscence Therapy Reminiscence-based interventions involve using life histories and experiences to improve well-being. [78]

12) Psychological Intervention – individual or group psychological treatment focused on enhancing adjustment and mood, using cognitive behavioural therapy (CBT), life review and/or on strategies to improve memory, using a cognitive rehabilitation approach [81]

13) Staff Development Intervention - staff training and support programs which target BPSD [78]

14) Social Intervention including Simulated Presence Therapy (SPT) – recordings of family members, including conversations, stories, or shared memories [80]
Table 2. Characteristics of included Reviews

<table>
<thead>
<tr>
<th>Article (Author, Year)</th>
<th>AMSTAR Quality Rating</th>
<th>Intervention(s) covered</th>
<th>Included RCTs</th>
<th>Meta-analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blythe and Chang, 2009</td>
<td>8</td>
<td>3, 8, 9, 10, 14</td>
<td>6</td>
<td>N</td>
</tr>
<tr>
<td>Brodaty and Burns, 2012</td>
<td>7</td>
<td>5, 6, 8, 10, 11, 14</td>
<td>4</td>
<td>N</td>
</tr>
<tr>
<td>Forbes et al., 2013</td>
<td>11</td>
<td>6</td>
<td>4</td>
<td>Y</td>
</tr>
<tr>
<td>Forbes et al., 2014</td>
<td>11</td>
<td>2</td>
<td>4</td>
<td>Y</td>
</tr>
<tr>
<td>Forrester et al., 2014</td>
<td>10</td>
<td>4</td>
<td>4</td>
<td>N</td>
</tr>
<tr>
<td>Fossey et al., 2014</td>
<td>10</td>
<td>10, 13</td>
<td>4</td>
<td>Y</td>
</tr>
<tr>
<td>Gonzalez and Kirkevold, 2013</td>
<td>7</td>
<td>7</td>
<td>1</td>
<td>N</td>
</tr>
<tr>
<td>Kong et al., 2009</td>
<td>8</td>
<td>7, 9, 14</td>
<td>5</td>
<td>Y</td>
</tr>
<tr>
<td>Kverno et al., 2009</td>
<td>8</td>
<td>4, 8, 14</td>
<td>5</td>
<td>N</td>
</tr>
<tr>
<td>Livingston et al., 2014</td>
<td>10</td>
<td>1, 8, 9</td>
<td>8</td>
<td>N</td>
</tr>
<tr>
<td>Livingston et al., 2005</td>
<td>7</td>
<td>1, 12</td>
<td>4</td>
<td>N</td>
</tr>
<tr>
<td>Pieper et al., 2013</td>
<td>8</td>
<td>9, 10</td>
<td>3</td>
<td>N</td>
</tr>
<tr>
<td>Reuther et al., 2012</td>
<td>8</td>
<td>13</td>
<td>2</td>
<td>N</td>
</tr>
<tr>
<td>Seitz et al., 2012</td>
<td>7</td>
<td>5, 6</td>
<td>4</td>
<td>N</td>
</tr>
<tr>
<td>Testad et al., 2014</td>
<td>7</td>
<td>5, 6, 11, 12, 13</td>
<td>13</td>
<td>N</td>
</tr>
<tr>
<td>Ueda et al., 2013</td>
<td>8</td>
<td>1</td>
<td>8</td>
<td>Y</td>
</tr>
<tr>
<td>Verkaik et al., 2005</td>
<td>8</td>
<td>8, 9, 12</td>
<td>4</td>
<td>N</td>
</tr>
<tr>
<td>Viggo Hansen et al., 2006</td>
<td>10</td>
<td>3</td>
<td>1</td>
<td>Y</td>
</tr>
<tr>
<td>Watson et al., 2012</td>
<td>11</td>
<td>3, 4, 6</td>
<td>8</td>
<td>N</td>
</tr>
<tr>
<td>Woods et al., 2009</td>
<td>11</td>
<td>11</td>
<td>1</td>
<td>Y</td>
</tr>
</tbody>
</table>

Synthesis of Results

Results from meta-analyses are summarised below. Table 3 summarises the results for each non-pharmacological intervention and reports the number of included studies and observations, effect size with confidence interval, significance level, heterogeneity statistic and list of symptoms significantly affected by intervention.
Table 3. Meta-Analyses of non-pharmacological Interventions

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Included RCTs</th>
<th>Observations (Experimental, Control)</th>
<th>SMD [CI], p-value</th>
<th>$I^2$</th>
<th>Statistically Significant Symptoms (observations), # RCT, effect size [CI], p-value, $I^2$ (N&gt;1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Music Therapy</td>
<td>12</td>
<td>857 (434,423)</td>
<td>-0.37 [-0.62, -0.13], p=0.003**</td>
<td>66%</td>
<td>• Anxiety (222), 6, -0.52[-1.03, -0.01], p=0.05, $I^2=67%$</td>
</tr>
<tr>
<td>Exercise Programs</td>
<td>9</td>
<td>1398 (695, 703)</td>
<td>-0.13 [-0.27, 0.01], p=0.07*,**</td>
<td>38%</td>
<td></td>
</tr>
<tr>
<td>Light Therapy</td>
<td>3</td>
<td>553 (347,206)</td>
<td>-0.16 [0.53, 0.21], p=0.40**</td>
<td>71%</td>
<td>• Apathy (36), 1, -0.99[-1.96, -0.01], p=0.05</td>
</tr>
<tr>
<td>Therapeutic Touch</td>
<td>5</td>
<td>263 (153,109)</td>
<td>-0.30 [-0.60, 0.00], p=0.05**</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td>Aromatherapy</td>
<td>4</td>
<td>472 (241,231)</td>
<td>-0.25 [-0.56, 0.06], p=0.11**</td>
<td>65%</td>
<td></td>
</tr>
<tr>
<td>Multi Sensory Stimulation</td>
<td>5</td>
<td>942 (467, 475)</td>
<td>-2.79 [-3.91, -1.67], p&lt;0.00001**</td>
<td>97%</td>
<td>• Agitation (267), 4, -0.89[-1.48, -0.30], p=0.003, $I^2=78%$</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Apathy (160), 3, -5.83[-10.36,-1.30], p=0.01, $I^2=99%$</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Anxiety (125), 1, -1.81[-2.23,-1.39], p=0.0001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Aggression (125), 1, -4.32[-4.96,-3.67], p=0.00001</td>
</tr>
<tr>
<td>Activities Based Intervention</td>
<td>3</td>
<td>260 (162,98)</td>
<td>-0.06 [-0.41, 0.53], p=0.80**</td>
<td>65%</td>
<td></td>
</tr>
<tr>
<td>Environmental Intervention</td>
<td>2</td>
<td>72 (37,35)</td>
<td>0.00 [-0.46, 0.47], p=0.99**</td>
<td>0%</td>
<td></td>
</tr>
<tr>
<td>Behavioural Intervention</td>
<td>2</td>
<td>134 (76,58)</td>
<td>-0.17 [-1.02, 0.68], p=0.70**</td>
<td>83%</td>
<td>• Depression (52), 1, -1.02[-1.62,-0.43], p=0.0008</td>
</tr>
<tr>
<td>Psychological Intervention</td>
<td>4</td>
<td>718 (413, 305)</td>
<td>-0.11 [-0.30, 0.08], p=0.26**</td>
<td>30%</td>
<td></td>
</tr>
</tbody>
</table>

1 This column shows the results from meta-analyses combining relevant RCTs. It states the number of RCTs included in the analysis for a symptom, the effect size, p-value and $I^2$ calculation where more than one RCT was included.
<table>
<thead>
<tr>
<th>Intervention</th>
<th>N</th>
<th>Sample Size</th>
<th>SMD</th>
<th>Lower CI</th>
<th>Upper CI</th>
<th>p-value</th>
<th>Significance</th>
<th>Effect Size</th>
<th>Percentage</th>
<th>Symptom(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person Centred Care</td>
<td>5</td>
<td>1164 (720, 444)</td>
<td>-0.56 [-0.98, -0.13], p=0.01**</td>
<td>91%</td>
<td>-0.79 [-1.31, -0.27], p&lt;0.003</td>
<td>Reminiscence Therapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Agitation (645)</td>
<td>-0.70 [-1.41, 0.01], p=0.05, I²=94%</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Aggression (60)</td>
<td>-0.79 [-1.31, -0.27], p&lt;0.003</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reminiscence Therapy</td>
<td>4</td>
<td>139 (71.68)</td>
<td>-0.50 [-0.84, -0.16], p=0.004</td>
<td>0%</td>
<td>-0.87 [-1.41, 0.14], p=0.004, I²=0%</td>
<td>Staff Development Intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Depression (119)</td>
<td>2, -0.51 [-0.87, -0.14], p=0.004, I²=0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Aggression (53), 1, 1.13[0.54,1.72], p=0.0002</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Intervention</td>
<td>3</td>
<td>184 (92,92)</td>
<td>-0.84 [-1.88, 0.20], p=0.11</td>
<td>88%</td>
<td>-4.92 [-4.92, 4.06], p&lt;0.00001</td>
<td>Social Intervention</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Depression (119)</td>
<td>2, -0.51 [-0.87, -0.14], p=0.004, I²=0%</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Aggression (53), 1, 1.13[0.54,1.72], p=0.0002</td>
<td></td>
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</tr>
</tbody>
</table>

* Nearing statistical significance
** Some participants counted twice due to RCTs reporting for different symptom outcomes within one study sample

Analysis of RCTs for non-pharmacological interventions for affective symptoms found statistically significant effects (SMD -0.52 [-0.69, -0.35], p<0.00001). However, this result is rendered uncertain by high heterogeneity of included studies (I²=92%) indicating incomparability of included studies. Subgroup analysis of intervention types revealed five significant effect sizes; Music (SMD -0.37 [-0.62, -0.13], p=0.003), Therapeutic Touch (-0.30 [-0.60, 0.00], p=0.05), Multi-Sensory Stimulation (SMD -2.79 [-3.91, -1.67], p<0.00001), Person Centred Care (SMD-0.56 [-0.98, -0.13], p=0.01), and Reminiscence Therapy (SMD -0.50 [-0.84, -0.16], p=0.004), and one nearing significance; exercise therapy (-0.13 [-0.27, 0.01], p=0.07). Although these show promise, samples were small. Further, it is unlikely that an intervention would act equally for all symptom presentations and thus this is likely to contribute to heterogeneity in included studies. Analysis of outcomes found four of five symptoms significantly influenced by non-pharmacological intervention; Depression (SMD -0.54 [-1.02, -0.05], p=0.03), Agitation (SMD -0.40 [-0.63, -0.18], p=0.0005), Anxiety (-0.51 [-0.93, -0.09], p=0.02) and Apathy (-2.15[-3.69, -0.61], p=0.006), with the exception of aggressive symptoms. However, it is unlikely that any intervention will equally influence these symptoms as these results could suggest and so it is insufficient to recommend non-pharmacological interventions for any sort without further distinction. Lack of distinction for interventions within symptom analysis is likely contributing to large heterogeneity due to the large diversity of intervention types used for each symptom, unique methodological approaches and varied methods of measurement. Given this, symptom analyses were further divided into their included intervention...
types. This division revealed twelve symptom and intervention combinations reaching statistical significance.

**Matrix of Evidence and Recommendations**

Specific recommendations on the effectiveness of an intervention can only be made when symptom by intervention analysis is performed. To illustrate, although pooled analyses for staff development interventions had a significant positive effect, it would be misleading to give a blanket recommendation for them for RB interventions as detailed analysis shows that Staff development interventions have positive effects for depression but produce negative effects for aggression. Similarly, the pooled analysis suggests that aggressive symptoms are not responsive to non-pharmacological approaches yet with intervention specificity it is revealed that aggression has statistically significant positive response to Multi-Sensory Stimulation (SMD -4.32 [-4.96, -3.67], p<0.00001) and Person-Centred Care (SMD -0.79[-1.31, -0.27], p=0.003) and has statistically significant negative response to Staff Development Interventions (SMD 1.13 [0.54, 1.72], p=0.0002). Clarification of recommendations can only be achieved when analysis by both outcome and intervention takes place. This review, in acknowledgement of this, developed a symptom by intervention comparison matrix in an attempt to generate clearer recommendations for care.

*Table 4* presents the level of evidence corresponding to interventions by outcome and summarises recommendations to improve evidence level. The shadings indicate the strength of the evidence such that interventions with moderate evidence or above could tentatively be recommended within care facilities for the management of matching affective symptom.
Table 4. Matrix of Intervention and Symptom Effect for level of evidence and recommendations

<table>
<thead>
<tr>
<th>Total</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Agitation</th>
<th>Apathy</th>
<th>Aggression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Music Therapy</td>
<td>a, c</td>
<td>a</td>
<td>a, b, c</td>
<td>b</td>
<td>b</td>
</tr>
<tr>
<td>Exercise Programs</td>
<td>b</td>
<td>a, b</td>
<td>a, b, c</td>
<td>a, b</td>
<td>b</td>
</tr>
<tr>
<td>Light Therapy</td>
<td>a, b, c</td>
<td>a, b</td>
<td>a, b, c</td>
<td>a, b</td>
<td>b</td>
</tr>
<tr>
<td>Therapeutic Touch</td>
<td>b</td>
<td>b</td>
<td>a, b</td>
<td>b</td>
<td>a, b</td>
</tr>
<tr>
<td>Aromatherapy</td>
<td>b</td>
<td>b</td>
<td>a, b</td>
<td>b</td>
<td>b</td>
</tr>
<tr>
<td>Multi Sensory Stimulation</td>
<td>a, b, c</td>
<td>a, b</td>
<td>a, b, c</td>
<td>a, b</td>
<td>a, b</td>
</tr>
<tr>
<td>Activities Based Intervention</td>
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<td>b</td>
<td>a, b, c</td>
<td>a, b</td>
<td>b</td>
</tr>
<tr>
<td>Environmental Intervention</td>
<td>b</td>
<td>b</td>
<td>a, b</td>
<td>b</td>
<td>a, b</td>
</tr>
<tr>
<td>Behavioural Intervention</td>
<td>a, b</td>
<td>b</td>
<td>b</td>
<td>b</td>
<td>a, b</td>
</tr>
<tr>
<td>Psychological Intervention</td>
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<td>a, b, c</td>
<td>a, b</td>
<td>b</td>
<td>b</td>
</tr>
<tr>
<td>Person Centred Care</td>
<td>a, b</td>
<td>b</td>
<td>c</td>
<td>b</td>
<td>a, b</td>
</tr>
<tr>
<td>Reminiscence Therapy</td>
<td>a, b</td>
<td>b</td>
<td>b</td>
<td>b</td>
<td>b</td>
</tr>
<tr>
<td>Staff development</td>
<td>a, b</td>
<td>b</td>
<td>b, c</td>
<td>b</td>
<td>a, b</td>
</tr>
<tr>
<td>Social Intervention</td>
<td>b</td>
<td>b</td>
<td>a, b, c</td>
<td>b</td>
<td>b</td>
</tr>
</tbody>
</table>

Key

Strong evidence
Moderate evidence
Limited evidence
Limited evidence against
Moderate Evidence against
Strong evidence against
No included evidence
Recommendations

- a. Sample size issues (n<300), Increase sample size
- b. Investigate ability for systematic review, if unable (N<4), perform RCTs
- c. Heterogeneity issues (I^2>75%), Investigate heterogeneity

The symptom by intervention matrix revealed only three analyses that provide sufficient evidence for the recommendation of management strategies. These are marked as having strong evidence within Table 4. These include music therapy for anxiety (-0.52[-1.03, -0.01], p=0.05, I^2=67%), staff development for depression (-4.49[-4.92, -4.06], p<0.00001) and person-centred care for aggression (-0.79[-1.31, -0.27], p=0.003). In this review, music therapy included interventions using group music, rhythmic exercise, calming music, preferred listening, use of percussion or instruments, active listening and singing. Staff development focused on the training in individualised care, dementia care mapping and psychosocial care and the effect of ongoing peer support. Person-centred care included individualised care plans, assessment and management of unmet needs, showering and towel-baths and dementia care mapping.

**Risk of Bias**

A funnel plot was used to investigate publication bias in the studies. The shape of the funnel plot for the global comparison indicated no obvious asymmetry (Figure 3). Furthermore, viewing funnel plots for statistically significant intervention types revealed no significant asymmetry. The Egger’s regression analysis (p=0.308) provided further evidence against the presence of publication bias.
Discussion

In response to the magnitude of available literature this review utilised a panoramic meta-analysis to identify non-pharmacological intervention for the management of affective symptoms of dementia. Analyses revealed statistically significant reductions in RB with non-pharmacological interventions providing evidence that non-pharmacological interventions can have a positive effect on affective symptoms. Despite this positive trend, this result is rendered uncertain by the heterogeneity of included studies. Delving further into this reveals various possible sources of heterogeneity. As the Cochrane handbook says “A common analogy is that systematic reviews bring together apples and oranges, and that combining these can yield a meaningless result. This is true if apples and oranges are of intrinsic interest on their own, but may not be if they are used to contribute to a wider question about fruit”. Applying this to our study would suggest that although interventions for various symptoms are covered by one umbrella of ‘affective interventions’, this may be too wide to combine within one analysis. Given this, the analysis was then divided into its symptom and intervention types. However, more sources of heterogeneity are possible here. This heterogeneity is likely to be due to the variation in
intervention implementation or study design, participant diversity, and variation in outcome measurement.

Individual non-pharmacological intervention did not positively influence all affective symptoms or allow for clear recommendations and thus further divisions by symptom and intervention within this analysis were necessary to draw conclusions.

Further analysis revealed that only three symptom by intervention combinations could be recommended including music therapy for anxiety, staff development for depression and person-centred care for aggression. On the basis of this panoramic analysis these represent the best options currently available for sources of evidence to support care practices. However, significant limitations to these analyses were evident in sample size, heterogeneity and number of included RCTs. Until the recommendations matrix reflects higher evidence levels, implementation of these interventions should be undertaken cautiously. Given this, it is premature to present these sources of evidence as definitive. It is more accurate to regard them as a general indication of best available evidence based on a limited literature. The panoramic method in this instance falls short of providing definitive recommendations but does give general insight into some positive interventions.

**Limitations and direction**

The panoramic method did not produce clear recommendations. This may be due to limitations such as no interventions having the sample size required to make generalizable conclusions and heterogeneity of outcome measures. Within pharmacology, a medication would not be recommended for widespread use without multi stage clinical testing with sample sizes of several thousand [100]. This review has a total of 8,361 observations across 14 distinct intervention types (mean 597.2 observations per intervention). There is some strong evidence for the effect of non-pharmacological interventions but not enough to create definitive conclusions. This review found support for three interventions within the matrix. However, all three had sample sizes less than 300 included in the analyses and two of the three had only one included RCT in its analysis. Although there is promise in these three symptom intervention combinations, caution must be applied when recommending these as a source of evidence in EBP. More research into all intervention types, as well as high quality systematic reviews and meta-analyses are needed to reach the level of rigour found in high quality medical research and to support the use of panoramic methods to identify sources of evidence to support RB care decisions.
This review focused on the group of affective symptoms as the literature shows them to be the most burdensome for the health and aged care systems. There would be merit in investigating other categories, however, this was beyond the scope of the current research. Although the researcher attempted to identify all eligible articles within the systematic search, researching using wider or different search parameters could identify articles which were overlooked. Similarly, assessing systematic reviews and meta-analyses using a different quality assessment could alter articles identified as ‘acceptable’ quality. Future systematic reviews and meta-analyses should look towards the AMSTAR and other quality assessments in the preparation of their reviews to avoid elimination from panoramic reviews. Fourteen intervention types were identified within the literature. Although a broad list, this does not necessarily represent the totality of available intervention types for affective symptoms. The inclusion of wider search parameters within included reviews could allow for a more comprehensive menu of interventions to assess the utility of the panoramic method. Heterogeneity was the largest limitation within this review. Heterogeneity across analyses was considerable suggesting they may include articles that are too diverse to compare. Future research is required to investigate sources of heterogeneity and should be designed in accordance with Cochrane guides to eliminate future syntheses facing similar phenomenon.

Although it is premature to identify best sources of evidence for care of affective RB, this panoramic review and resulting matrix do enable clear recommendations for research. No one intervention type was tested for all affective symptoms, or any symptom held against all interventions and thus there is a large gap within this research. It is impossible to conclude any intervention is best for a symptom without complete literature for each intervention for each symptom and thus future research should aim to address recommendations within the matrix. Researchers should aim to bring all symptom intervention combinations to an adequate standard by addressing the three main recommendations which are presented within the matrix structure; 1) to increase sample size if there are sample issues (n<300); 2) to perform systematic reviews if there is adequate literature (N>4) or conduct RCTs to build literature; and 3) to investigate issues of heterogeneity if analyses had high heterogeneity \( (I^2>75\%) \). By addressing these recommendations within the matrix structure, the ability for panoramic methods to provide best evidence will be strengthened.

In line with current guidelines and evidence hierarchies, this review included only RCT studies. However, RCTs are cumbersome to conduct within RACF environments, especially for samples including residents with
dementia due to varying levels of cognitive decline and behavioural disruption [101] making the study population difficult to engage in intervention studies involving controlled research design. Furthermore, environmental factors such as facility policy, staff non-compliance issues and turnover rates limit the number of RCTs conducted for RB and reduce the plausibility of RCTs as a means for best evidence [101]. In parallel, only RCTs included within previous synthesis reviews were included in the analyses and many primary studies may have been missed. Search strategies that included primary studies, could have neutralised this limitation but was not done in the current study to limit included studies to manageable scope.

**Questioning the “holy grail” in research with people with dementia**

In accordance with meta-analysis guidelines set out by The Cochrane Collaboration [66] and in the interest of external validity, this review did not include non-randomised studies (NRS). However, exclusion of NRS does violate the notion of total evidence and limits the ability to judge a hypothesis as ‘informed’ [61]. This is particularly relevant in this review given the difficulty performing RCTs in the target population making NRS often more appropriate than studies involving controlled research design [102]. The reality is that the homogeneity necessary for successful RCT experimentation may be unobtainable when exploring social or psychological phenomenon in diverse human populations - with RB a prime example [102]. These challenges occur within the biomedical model and the dominance of medical research to explain all disease in biological terms, ignoring the impact of psychological and social factors of any condition [102]. The biomedical model has long been claimed to be an example of objective science using quantitative methods such as the RCT and the only valid perspective for understanding disease and illness [103]. Deductive methods result in a narrowness of scope [104]; that is, misrepresentation of the complexities intrinsic to the humanity attached to human populations. Without the respect of these complexities we are in danger of robbing those with dementia of their humanity and relegate them to the status of objects of study [105]. Inclusion of NRS or a mixed-method approach is likely to be necessary to identify the best sources of evidence for interventions for RBs in the people with dementia under consideration in this study.

Although RCTs have high internal validity, when properly implemented they put constraints on population eligibility and thus reduce external validity [104]. This restriction often eliminates those from culturally or linguistically diverse backgrounds, those with disability, on medications or with co-morbidity and thus any
results are not generalizable to the majority of those with dementia who have at least one of these or other co-
variates. Furthermore, measurement tools for RB have not been developed or evaluated for diverse populations
[106] and thus results using non-validated tools cannot be considered accurate for diverse groups. These
methods decrease generalisability through sampling criteria whilst simultaneously increasing social inequity
through the inclusion of only those who match the majority; usually those from English-speaking backgrounds,
without disability, and are high functioning or in the earlier phases of the disease.

The matter of external validity in dementia research poses the question; why are RCTs and meta –analyses of
RCTs held as the ‘platinum’ evidence base for studying RB and other dementia-related conditions? The answer
lies in distribution of funding. This issue has been dubbed “The Elephant in the Room” for dementia research
[107], an issue directing research decisions which is often overlooked. Today, grant funding bodies focus on
determining the efficacy of intervention which privilege research with quantitative methods such as RCTs [108].
As a result, research into the qualitative nature of diseases such as psychological and social determinants are
underfunded and viewed as ‘soft-sciences’. Biomedical models ignore social and psychological phenomenon
[102], yet the methodologies from this are illogically adopted when studying the social and psychological
implications in dementia. The quantitative bias at work in funding bodies dictates that qualitative research grant
applications are judged using quantitative criteria leading to perceptions that the research is ‘soft’ or less
generalizable than quantitative counterparts [109]. This leaves qualitative researchers with no option but to
adopt mixed-methods approaches that appear viable for external grants [109] often at the cost of meaningful
exploration. Additionally, synthesis of mixed methods research further complicates issues with severe statistical
issues when trying to combine unmatched non-randomised trials resulting in low internal validity [66].

The RCTs that dominate medical fields may be unable to deal with the complexities of working with people
with dementia with all of their associated complexities, suggesting the need for a new method for synthesis that
allows for individual difference, social theories and diversity without sacrificing rigor. Best practice hierarchies
suggest that when systematic reviews and RCTs fail to support evidence based decisions, care staff should adopt
the next level in the best practice, ‘evidence based clinical practice guidelines’ [52]. Research into the
knowledge translation within health fields suggests that when synthesis such as meta-analyses are unable to
produce clear care recommendations, then attention must move towards other forms of sources of evidence
including expert opinion or evaluation of CPGs [51], [110]. This evaluation is needed to replace quantification
of effect sizes with such considerations as expert opinion, quality, useability and resident outcomes.

**Conclusion**

This study aimed to discover if panoramic syntheses can identify best sources of evidence to support the non-pharmacological intervention of the affective symptoms of RBs. However, this study was unable to do so owing to large heterogeneity and sampling issues within included RCTs. Although the panoramic methodology was unable to produce best evidence in this review, it did reveal positive associations for the non-pharmacological interventions for affective symptoms and was able to generate three tentative recommendations for evidence based care practices. The method revealed various interventions that are promising for the reduction of RB but the evaluations do not yet have sufficient statistical power to allow confident clinical recommendation of best evidence due to limitations such as small sample sizes and heterogeneity.

It becomes evident that gold standards from the reductionist biomedical model that dominate medical fields may have failed to grasp the complexities when working with people with dementia and attached complexities suggesting the need for a new method for synthesis that allows for individual difference, social theories and diversity without sacrificing rigor. Best practice hierarchies suggest that when systematic reviews and RCTs fail to support evidence based decisions, care staff should move towards the next level in the best practice, ‘evidence based CPGs based on systematic reviews of RCTs’ [52]. However, recent syntheses of CPG have not been adequate to support consensus [111]. While research would benefit from exploring methods of synthesis beyond meta-analysis of RCTs, care staff require assistance to evaluate the next best level in the best practice hierarchy, CPGs [52]. This evaluation will need to replace quantification of effect sizes with such considerations as relevance, quality, useability and resident outcomes. Beyond research syntheses, KT research nominates alternative sources of evidence as clinical practice guidelines and expert opinion[51], [110].
Chapter 3 – Identification and Assessment of Quality in Clinical Practice Guidelines for Responsive behaviours

Background

For those seeking non-pharmacological approaches, Clinical Practice Guidelines (CPGs) can support clinical decision making to guide the appropriate intervention for RB [111]. CPGs are “evidence based statements that include recommendations intended to optimise patient care and assist health care practitioners to make decisions about appropriate health care for specific clinical circumstances” [36]. CPGs are often developed by multidisciplinary expert panels to present evidence-based care recommendations to healthcare practitioners and care staff. Best practice hierarchies suggest that when synthesis methodologies, such as panoramic reviews, are unable to identify best sources of evidence to direct EBP then ‘evidence based clinical practice guidelines (CPGs) based on systematic reviews of Randomised Control Trials (RCTs)’ constitute the next level in best practice [52].

However, current guidelines may be unhelpful due to a lack of consistency in their recommendations and generally weak or low quality evidence informing their development [111]. Clinicians seeking support for the non-pharmacological care of RB are often overwhelmed by choice of CPG and have little guidance available to determine which available CPGs are of an acceptable quality. Available CPGs must be critically appraised for methodological quality to ensure that guidance is based on credible evidence [112]. The ability of CPGs to facilitate clinical decision-making and improve care is proportional to their quality, so that if developed on low-quality evidence they may perpetuate inaccurate treatment advice and poor practice [113]. Given this context, it is logical to explore clinical guidelines as a source of evidence to determine which are readily accessible and then to evaluate their quality so that clinicians will be better placed to select the guideline(s) most likely to be of help to them.
Method

Systematic Search

A search of the literature was performed to identify CPGs for comparison with the iCAHE Guideline Quality Checklist Scores to determine if available guidelines are based on evidence that is of an ‘acceptable’ level.

A systematic search for existing CPGs for the management of RBs (or BPSD) was performed in Scopus, Cochrane, PubMed, Medline, EMBASE, CINAHL databases in July, 2015. This followed the JBI Reviewer’s Manual three phase search strategy outlined in Section 2.6.5- Search Strategy [114]. Search strings included suitable indexing terms (i.e., MeSH terms and keywords) on (1) dementia (e.g., dementia; Alzheimer’s disease), (2) Clinical Practice Guidelines and (3) BPSD (e.g., apathy, neuropsychiatric, affective) (see Appendix B for full search strategy).

The following keywords were used;

Dementia OR Alzheimer*

AND

Guid* OR clinical OR Manag* OR practice OR consensus

AND

neuropsychiatric OR BPSD OR behav* OR psycholog* OR non-cognitive OR affect* OR anxi* OR agitat* OR depress* OR aggress* OR apath* OR irritat* OR mood

Search limits included articles published in English between 2005 and July, 2015. Grey literature was searched in July, 2015. This included search of organisations that have produced clinical guidelines such as national Alzheimer’s Associations, Dementia Behaviour Management Advisory Service (DBMAS) and the National Health and Medical Research Council (NHMRC) Clinical Practice Guidelines Portal. Further, Google and Google Scholar search engines were searched using the search terms ‘dementia’ and ‘guidelines’.
Guideline selection and inclusion criteria

PICOS

This study adopted the Cochrane Collaboration suggested PICOS framework (Participants, Interventions, Comparators, Outcomes, Study Design) [66] in the development of its inclusion criteria.

Participants

This study considered studies focusing on participants with a dementia diagnosis living within Residential Aged Care Facilities (RACF). Studies that included participants with dementia as part of a broader population were considered only if it was possible to extract data relating only to those with dementia.

Intervention

Interventions addressing the non-pharmacological management of one or more affective symptom within studies were considered relevant in this review.

Comparators

Control groups with “no treatment” or “care as usual” for matched participants were considered.

Outcome

Responsive behaviours were the primary outcome measure. Articles including guidelines which referenced one or more responsive behaviour were deemed relevant.

Study

Articles were included if they addressed one or more clinical practice guideline for non-pharmacological management of responsive behaviours.

Titles and abstracts of retrieved citations were screened by one author (CK) using the broad criterion that the article included description of the management of one or more responsive behaviour for those with a dementia diagnosis living within RACFs. If considered relevant, full-text guidelines were retrieved. Full text articles were screened by one author (CK).
Assessment

This research utilised the Intervention Centre for Allied Health Evidence (iCAHE) Guideline Quality Checklist to test the quality of evidence within guidelines. While the AGREE II Instrument is a research focused quality assessment for CPGs and is the most commonly used within the current literature [115], the iCAHE is considered to have some advantages in this research. It has been tested against the AGREE II for Content and construct validity, inter-tester reliability and clinical utility [116]. Further it was found correlating for Scope & Purpose, Stakeholder involvement, Underlying evidence / Rigour, and Clarity with the AGREE II [116]. The iCAHE has advantage in this instance over the AGREE II due to its clinical focus and the need to disseminate quality evidence within clinical settings. It is therefore most appropriate for KT strategies which aim to promote EBP. Furthermore, the iCAHE was found to be easier to use, take less time, and it can be used by a single assessor with no prior training [116]. The iCAHE uses criteria such as included search criteria, availability as full-text, review process and useability in its evaluation of CPG quality. Although more appropriate in this instance, the iCAHE has disadvantage in its management of conflict of interest assessment. It has lower correlation with the AGREE-II Domain 6 – Editorial Independence [117] which identifies if ‘Competing interests of guideline development group members have been recorded and addressed’. However, given its high correlation with AGREE-II Scores, it is the most appropriate clinician-focused rapid assessment tools.

Data Abstraction and Quality criteria

A form was developed to extract the following CPG characteristics; title, publication date, organization, country, developed methods, number of references, topics covered and the 14 items of the iCAHE Quality Checklist (Appendix A). The iCAHE assessment of guidelines was conducted by one researcher (CK). A quality cut-off standard was set at 65% (9/14 possible score) within iCAHE assessments. This cut off was chosen in response to the Australian NHMRC typically approving CPGs that reach a quality score above 65% on AGREE assessments and the high correlation between these two assessment tools [68]. Guidelines were considered ‘high’ quality if iCAHE scores were higher than this cut off (>9/14).
Coding of Recommendations

High quality guidelines were manually scanned and coded by one author to identify and compare recommendations for care. This was categorised by symptom and associated recommendations (if any). See Table 7.

Results

A total of seven guidelines for the non-pharmacological care of RB were identified via systematic search and subject to quality assessment using the iCAHE checklist. Three guidelines were sourced from Australia, with others coming from British Columbia, United Kingdom and international associations. The majority of identified guidelines were produced or updated in 2012 (71.4%).
<table>
<thead>
<tr>
<th>Name</th>
<th>Year</th>
<th>Location/Source</th>
<th>iCAHE Score/14</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviour Management: A Guide to good Practice</td>
<td>2012</td>
<td>DBMAS, Australia</td>
<td>12</td>
</tr>
<tr>
<td>Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD) A Handbook for NSW Health Clinicians</td>
<td>2013</td>
<td>NSW Ministry of Health and the Royal Australian and New Zealand College of Psychiatrists, Australia</td>
<td>9</td>
</tr>
<tr>
<td>The IPA Complete Guides to BPSD – Nurses Guide</td>
<td>2012</td>
<td>International Psychogeriatric Association</td>
<td>8</td>
</tr>
<tr>
<td>Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care: A Person-Centered Interdisciplinary Approach</td>
<td>2012</td>
<td>British Columbia</td>
<td>8</td>
</tr>
<tr>
<td>Reducing Behaviours of Concern (ReBOC)</td>
<td>2012</td>
<td>DBMAS, Australia</td>
<td>7</td>
</tr>
<tr>
<td>Management of the behavioral and Psychological symptoms of dementia</td>
<td>2013</td>
<td>NaRCAD (the National Resource Center for Academic Detailing), Boston</td>
<td>6</td>
</tr>
</tbody>
</table>
Table 6. iCAHE Assessment of Identified Clinical Practice Guidelines

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<tr>
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<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>TOTAL</th>
</tr>
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<tbody>
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<td>Is the guide readily available in full-text?</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>X</td>
<td>x</td>
<td>X</td>
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<td>Full reference list provided?</td>
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<td>x</td>
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<td>X</td>
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<td>100%</td>
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<td>Summary of recommendations provided?</td>
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<td>X</td>
<td>X</td>
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<td>Provides date of when literature was</td>
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<td>X</td>
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<td></td>
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<td></td>
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<td>Strategy for finding literature clear?</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>28%</td>
</tr>
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<td>recommendations</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Developers clearly stated</td>
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<td>X</td>
<td>x</td>
<td>X</td>
<td>X</td>
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<td>100%</td>
</tr>
<tr>
<td>Does developers qualification link to</td>
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<td>x</td>
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<td>X</td>
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<td>X</td>
<td>X</td>
<td>100%</td>
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<td>purpose of guide and end-users</td>
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<td>X</td>
<td>x</td>
<td>x</td>
<td>X</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td>100%</td>
</tr>
<tr>
<td>Readable and easy to navigate</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>86%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>13</td>
<td>12</td>
<td>9</td>
<td>8</td>
<td>8</td>
<td>7</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>

Of the seven guidelines identified, three were found to have an acceptable iCAHE score based on a 65% acceptability score (9/14 possible score); Behaviour Management: A Guide to good Practice (DBMAS), NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care and Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD) A Handbook for NSW Health Clinicians. Two guidelines, Behaviour Management: A Guide to good Practice (DBMAS) and NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care (NICE-SCIE), were considered of ‘high’ quality based on iCAHE scoring greater than 65% (>9/14 possible score).
The majority of guidelines scored for questions regarding availability (100%), references (100%), completion date (100%), developer details/purpose (100%), purpose/target audience (100%) and usability (86%). The majority of guidelines did not score for questions regarding summary of recommendations (57%), review dates (0%), details of literature search (date, strategy 43%), hierarchy of evidence (14%), appraisal of evidence (28%) and the link between hierarchy and appraisal (28%).

The Behaviour Management: A Guide to good Practice (DBMAS) is a 190-page guide which separated Modules according to symptom types. It uses the term BPSD to refer to the variety of RB interventions. It uses a person-centred approach with specific considerations when working with CALD and Indigenous populations. The NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care, in comparison, consisted of 392 pages with only one dedicated section regarding non-pharmacological interventions for RB. It uses the term non-cognitive symptoms or “behaviours that challenge”. There is no symptom categorisation which made navigation of the evidence more difficult.

In regard to care recommendations for general RB, aggression and nocturnal disruption, there was overlapping conclusions between the two high-quality guidelines. Both recommended person-centred approaches for general RB with the NICE-SCIE specifying the A-B-C (antecedents-behaviour-consequences) model, individualised interventions for aggression and sleep hygiene interventions for nocturnal disruptions. For general RB, the NICE-SCIE gave evidence for aromatherapy and staff training as well as person-centred approaches. The DBMAS guide gave some support for light massage, individual behavioural therapy, bright light therapy and Montessori activities in addition to the mutual recommendation of individual interventions. There was some overlap in individualised and person-centred approaches between the two guides, but also large discrepancy for sensory approaches. For Agitation, the DBMAS recommends music as best evidence where the NICE-SCIE recommends Aromatherapy and some support for doll therapy. There was some overlap for depression as the NICE-SCIE recommends group-based CBT, where DBMAS recommends behavioural approaches plus exercise programs. While both recommended hygiene interventions for nocturnal disruption, the NICE-SCIE also recommends daily walking and increased light exposure.

No specific evidence or recommendations were given by the NICE-SCIE for Anxiety, Apathy, Disinhibited Behaviours, Psychotic Symptoms, Vocal Disruptive Behaviours or Wandering.
The DBMAS guide divided evidence into symptom modules for ease of navigation, had a more complete approach to symptoms, and allows for clear conclusion regarding CALD and indigenous groups and has the benefit of symptom specific modules. However, the hierarchy of CPGs using the iCAHE quality assessment identified the NICE-SCIE as higher than the DBMAS. Although the hierarchy was able to identify which guidelines were of high quality it did not support the CPG with the clearest care recommendations and is thus inadequate in isolation to identify the best sources of evidence to support care decisions for RB.
Table 7. Comparison of High Quality CPGs

<table>
<thead>
<tr>
<th></th>
<th>DBMAS</th>
<th>NICE-SCIE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General RB</strong></td>
<td>Person-centred approaches focusing on</td>
<td>A-B-C model*, Aromatherapy, staff training</td>
</tr>
<tr>
<td></td>
<td>underlying causes*</td>
<td></td>
</tr>
<tr>
<td><strong>Aggression</strong></td>
<td>Individualised psychosocial interventions*,</td>
<td>individualised Behavioural intervention involving carers *</td>
</tr>
<tr>
<td></td>
<td>some support for light massage, individual</td>
<td></td>
</tr>
<tr>
<td></td>
<td>behaviour therapy*, bright light therapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>and Montessori activities</td>
<td></td>
</tr>
<tr>
<td><strong>Agitation</strong></td>
<td>Music therapies</td>
<td>Aromatherapy, some evidence for doll therapy</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>Multicomponent interventions which target</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>environmental, biological and psychosocial</td>
<td></td>
</tr>
<tr>
<td></td>
<td>factors contributing to anxiety. Some</td>
<td></td>
</tr>
<tr>
<td></td>
<td>evidence for music, Montessori, and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>psychotherapies.</td>
<td></td>
</tr>
<tr>
<td><strong>Apathy</strong></td>
<td>Therapeutic recreation using “question-asking</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>reading”, small group, individual/tailored,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Montessori based and kit-based activities.</td>
<td></td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>Exercise and behavioural approaches*</td>
<td>CBT Groups*</td>
</tr>
<tr>
<td><strong>Disinhibited Behaviours</strong></td>
<td>Limited support for psychoeducation/psychotherapy and behaviour modification</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Nocturnal Disruption</strong></td>
<td>The NITE-AD intervention using sleep hygiene education*</td>
<td>Sleep hygiene education*, daily walking and increased light exposure</td>
</tr>
<tr>
<td><strong>Psychotic Symptoms</strong></td>
<td>GentleCare Program</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Vocally Disruptive Behaviour</strong></td>
<td>Therapeutic recreation, limited for sensory (aroma, music, touch) and outdoor activities.</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Wandering</strong></td>
<td>Environmental interventions, sensory</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>interventions and touch therapies categories.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Some evidence for exercise and music studies.</td>
<td></td>
</tr>
</tbody>
</table>

*Overlapping recommendations

**Discussion**

CPGs are often a first-line approach to support clinicians in the non-pharmacological care of RB. However, there are multiple CPGs available and little guidance available to identify which available guidelines are of an acceptable quality. In response, this study aimed to investigate if evidence appraisal was helpful method for identifying CPGs as a source of evidence which support clear recommendations for practice. First, it identified which clinical guidelines were available for the non-pharmacological care of RB and then it used the iCAHE quality assessment to rank according to quality standard.
There was great variation between the seven identified guidelines based on iCAHE quality assessment scores, methods of development and their quality, comprehensibility and clinical recommendations. Three of seven guidelines were of an acceptable level based on the 65% acceptance level and only two of these were considered to be ‘high’ quality (>65%); Behaviour Management: A Guide to good Practice (DBMAS) and NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care. Variation between these high quality guidelines and other assessed guideline were largely seen in regard to inclusion of recommendation summary which allows for ease of use, search strategy including dates which give indication of being ‘up to date’ and the inclusion and link between a hierarchy and appraisal of evidence indicating quality of included evidence. This variation in quality gives further evidence of the perplexing choice for care staff when faced with RB and the need to clarify CPG choice to promote EBP.

There was some correlation between the recommendations of the two identified high-quality guidelines, but also large differences and gaps in recommendations, which made it difficult to identify best evidence. The DBMAS guide had a more complete schedule of symptom recommendations and divided evidence into symptom modules for ease of navigation. However, variation between the two high quality CPGs raised concerns regarding ability of this method of identify best sources of evidence to inform care staff. The appraisal of CPGs ranked the NICE-SCIE higher than the DBMAS despite the advantages seen in the latter in regard to care recommendations for more symptoms and specificity of recommendations. It became evident that, although the iCAHE assessment was able to identify high-quality CPGs, it did not support the CPG which allowed for clearest care recommendations. This may reflect the issue that quality assessments may not reflect the practicalities of guideline use within Australia. Guideline selection may not be as simple as ranking quality and selection of the highest. Investigations into clinical expertise regarding how clinicians select and recommend guidelines was a logical progression in this investigation.

Guidelines with lower scores could improve quality assessment scores by addressing common pitfalls. For time short staff providing care for those with a dementia diagnosis, quickly being able to access care recommendations is invaluable yet the majority of guidelines failed to include a summary of recommendation. This adaption is paramount to enable translation of research evidence into practice. No identified guideline indicated an anticipated review date. Although this factor may not be critical for direct care, it does indicate an
effort to remain up to date for researchers. It is suspected that review dates may be attached to affiliate websites rather than in guidelines themselves. Quality of included evidence was a primary area where guidelines lacked. In this, the majority failed to provide dates of when included literature was provided and the search strategies for finding literature. It is important to ensure evidence is up to date and thus guidelines should endeavour to rectify this neglect. A hierarchy to rank evidence allows care staff to determine front line treatments and subsequent treatments based on reliable evidence. Similarly, the evidence within guidelines and these hierarchies must be subject to appraisal to give indication of evidence strength behind care recommendations. Unfortunately, hierarchy and appraisal of evidence were very underrepresented in the identified guidelines. Improving these areas would facilitate the application of quick and efficient care strategies based on high quality evidence.

Limitations

This research used a systematic search to identify CPGs. Although the researchers tried to identify all eligible guidelines, researching using wider or different search parameters could identify guidelines overlooked. Similarly, assessing guidelines using a different quality assessment could alter guidelines identified as ‘acceptable’ quality. This is particularly so in regards to identification of Conflicts of Interest.

Conclusion

An abundance of research literature has led to a perplexing state for care staff when selecting CPGs as a source of evidence for the non-pharmacological care of RB. This study aimed to first discover which guidelines were accessible and then to rank these according to quality standard to clarify choice for care. Of seven identified CPGs, three were of an acceptable level and two were considered ‘high quality’; Behaviour Management: A Guide to good Practice (DBMAS) and NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care. Although the DBMAS guide allowed for clearer recommendations, was more complete and divided evidence into symptom modules for ease of navigation, it was ranked below the NICE-SCIE. This may be due to the assessment of CPGs not reflecting the practicalities of CPG use within practice. Although assessment and rank of CPG quality was a viable means to identify high quality guidelines, it was insufficient in isolation to determine best sources of evidence to support care staff regarding the non-pharmacological alleviation of RB. Further investigation into clinical expertise regarding the selection and recommendation of CPGs within a practical sphere was a logical next step in this investigation.
Chapter 4 - Components that influence expert recommendation and the Quality of Evidence included in recommended guidelines – a focus on affective symptoms in dementia.

Background

For those seeking non-pharmacological approaches, clinical practice guidelines (CPGs) can support clinical decision making to guide the non-pharmacological management of the RB [111]. Care staff within RACFs require ongoing support and the provision of easy-to-use research tools such as CPGs to improve EBP [35]. Despite a number of CPGs being available, there is little guidance in the selection of appropriate guidelines to facilitate the use of evidence in practice [11]. In time constrained RACFs, it is difficult for care staff to allocate time and focus from resident care to investigate EBP and thus accessible and user-friendly sources of evidence consolidating EBP is needed [13]. To date, systematic review and meta-analyses have been unable to identify best sources of evidence to support practice when caring for responsive behaviours (RB). Best practice hierarchies suggest that when these methodologies are unable to generate clear evidence to support practice decisions, ‘evidence based clinical practice guidelines (CPGs) based on systematic reviews of RCTs’ constitute the next level of evidence to be used in support of EBP.

However, choice of CPGs is complicated by a number of factors. These include

- the lack of consistency among guidelines recommendations
- generally weak or low-quality evidence informing guideline development [111]
- low correlation between the results of quality assessment and clear recommendations or the usability of CPGs to support care in practice

In line with this, a review of dementia care guidelines in Europe found inconsistency in methodological quality and inclusion of recommendations for psychosocial interventions [118] for RB in people with dementia. A systematic review of recent dementia CPG including the alleviation of RB [111] found no clear messages by consolidating recommendations from nine resources that address their non-pharmacological intervention.
Mixed messages were found for most interventions and none were included in a sufficient number of guidelines to generate clear recommendations. Research into the effective transfer of knowledge into practice decisions suggests that when synthesis of the literature is inadequate to support evidence-based care decisions, then focus must be shifted towards other sources of evidence including expert opinion [51], [110]. Given this complex picture of the strengths and weaknesses of guidelines, this research surveyed experts regarding their use of CPGs in actual practice and identify those characteristics of the guidelines that are associated with a recommendation of use.

Further, caution must be applied when comparing generalised CPG recommendations with symptom sub-groups that have distinctive incidence, trajectories over time, biological correlates, psychosocial determinants and unique responses to management strategies [11]. It is thus likely that recommendation of guidelines in reference to specified sub-syndrome would vary to that of a blanket RB recommendation. The affective cluster has been described as the most burdensome within the healthcare system as it encompasses the three most prevalent non-cognitive symptoms within dementia; apathy, depression and anxiety [11], [60] as well as aggression and agitation [15], [57].

This study aimed to determine if expert opinion on CPGs is an appropriate method for synthesising research to identify best sources of evidence regarding non-pharmacological RB alleviation. In this, it identified the CPGs that are currently being recommended by experts to care workers’ for the alleviation of RB in residential facilities, included care strategies, the components of a CPG that contribute to their recommendation, alternatives care support systems and comparison with recommendation made for affective-only symptoms. As the importance of methodological quality and evidence-base cannot be overlooked [116] this research aimed to consolidate expert recommendations with quality assessment of CPGs to determine if expert recommendations concur with ‘acceptable’ levels via the iCAHE evidence quality assessment.

**Methods**

**Survey Design**
A descriptive cross-sectional survey design was adopted to explore experts’ recommendation of CPGs at the time of survey. The aims of the survey were to understand factors influencing expert recommendations of CPGs, professional preference of CPG, features which contribute to their recommendation, recommendation with a focus on affective symptoms and any additional support systems they recommend to assist care workers to appropriately respond to RB.

**Guideline Selection**

Guidelines were selected using the Systematic Search, inclusion criteria PICOS and

*Data Abstraction and Quality criteria outlined in Chapter 3.*

**Survey Instrument Development**

A web-based survey was developed using Qualtrics software by one author (CK) to explore expert recommendation of CPGs for the non-pharmacological management of affective symptoms of dementia within residential facilities. Prior to distribution, the survey was piloted using think-aloud processes to ensure that the survey questions were clear, understandable and capable of collecting appropriate information. The think-aloud technique was used with a convenience sample of five DBMAS consultants via phone interviews to ensure face validity [119], [120]. All phone conversations were audio-recorded. Participants were asked to read and answer each survey item while explaining their thought processes out-loud. For each survey item, participants were asked about the clarity of wording, ease of understanding, technical issues, appropriateness of answer choices and had opportunity for any further comments. Based on the results, survey items were altered and survey format adjusted.

The final survey contained seven question regarding CPGs for the alleviation of RB. The term BPSD was used over responsive behaviours in this survey due to its prevalence and commonplace within the literature and available CPGs which are familiar to participants.

The following descriptive and demographic questions were included in the survey; age, gender (Male, Female,
Other (please specify)), state of employment and professional background (academic, aged care provider, nursing, medicine, psychology, social work, occupational therapy, other).

The final version of the survey was designed for completion via the web using Qualtrics software. The survey was made available in a web-browser and smart phone-app format.

Table 8. Survey Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past 6 months, have you recommended any clinical practice guidelines to direct care staff (e.g. nurses or attendants who provide direct care of residents) to support their non-pharmacological management of BPSD in the residential setting?</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>In the past 6 months, which of these guidelines have you recommended to direct care staff (e.g. nurses or attendants who provide direct care of residents) to support their non-pharmacological management of BPSD in the residential setting?</td>
<td>List of identified Guidelines.</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Unfamiliar with guide</td>
</tr>
<tr>
<td>If asked to recommend clinical practice guidelines, which would you select as your first three recommendations to support direct care staff within a residential setting in their non-pharmacological management of BPSD? Please indicate the order of your recommendations. *</td>
<td>List of identified Guidelines.</td>
</tr>
<tr>
<td></td>
<td>First preference</td>
</tr>
<tr>
<td></td>
<td>Second preference</td>
</tr>
<tr>
<td></td>
<td>Third preference</td>
</tr>
</tbody>
</table>
How would you rate the importance of the features listed below in contributing to your recommendations of clinical practice guidelines to direct care staff in residential care facilities for the non-pharmacological management of BPSD? *

<table>
<thead>
<tr>
<th>Feature</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ease of access (e.g. online pdf download)</td>
<td></td>
</tr>
<tr>
<td>Ease of use</td>
<td></td>
</tr>
<tr>
<td>Quality of included Evidence (e.g. based on systematic review of RCTs or experiential opinions)</td>
<td></td>
</tr>
<tr>
<td>Source (e.g. Department of Health or a university group)</td>
<td></td>
</tr>
<tr>
<td>Format (e.g. iphone app or hard copy booklet)</td>
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</tr>
<tr>
<td>Complexity of language (medical terms or a simple description)</td>
<td></td>
</tr>
<tr>
<td>Content (e.g. identifies appropriate intervention for symptoms, instruction for applying interventions)</td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
</tr>
<tr>
<td>Scale: Not at all Important – Extremely Important</td>
<td></td>
</tr>
</tbody>
</table>

*Repeated with reference to affective symptoms only.

**Recruitment and sampling**

The survey was distributed via email to 54 participants working as behaviour consultants within the Dementia Behaviour Management Advisory Service (DBMAS), Australia. DBMAS is an Australian Government funded organisation charged with the responsibility of providing care and advice to those with dementia and their professional and personal carers [121]. While the DBMAS is now a single national organisation at the time of the survey the DBMAS services were provided by state based organisations. The DBMAS consultants were identified as experts in RB intervention as they are a front-line response for management of symptoms of dementia and represent diverse multi-disciplinary advisory teams.

Participants were sent a brief description of the study via email and a website link which directed them to the Participant Information Sheet, Consent Form and survey questions. The survey was available in a web-browser or smart phone-app format. Reminder emails were sent at 2 week intervals and verbal reminders were given by
DBMAS team managers on two occasions. Ethics approval was obtained via the Human Research Ethics Committee at the University of Wollongong: consent to participate was indicated via an online checkbox prior to survey questions.

**Data Analysis**

The survey data were coded and analysed using Qualtrics software and SPSS v.21. Pearson correlations were used to assess correlation between nominal responses and t-tests and ANOVA were used for comparison of ranks.

**Results**

A total of 27 experts, 77% female, completed the survey (response rate of 50%). The median age bracket of respondents was 46-55 ($M=48.6$, $SD=1.14$: range 18-25 to Over 55). Participants were predominately from nursing background (62%) followed by occupational therapy (15%), psychology (12%) and education (12%). Consultant location was distributed across six states:

- Victoria 32%
- Western Australia 20%
- Queensland 16%
- New South Wales 12%
- Northern Territory 12%
- South Australia 4%
- Australian Capital Territory 4%

**Recommendation of Guidelines**

*Figure 4* displays participant indication of recommendation and familiarity with each CPG. The highest-rated guideline for alleviation of RB was the *Behaviour Management: A Guide to Good Practice*. Of the 96% who indicated they had recommended guidelines previously, 100% had recommended this guideline within the
previous six-month period. This was followed by Reducing Behaviours of Concern (ReBOC) guideline with 88% and the Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD) A Handbook for NSW Health Clinicians with 28% of participants having recommended these guidelines respectively within the previous 6 months.

![Figure 4. Rates of Guidelines Recommendation and Familiarity](image-url)
Table 9. Guideline Recommendation Data

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<td></td>
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<td>Unfamiliar 12 0 0 6 8 9 10</td>
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<td>RB</td>
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</tr>
<tr>
<td></td>
<td>Second 1 7 10 3 0 1 2</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Third 1 1 5 8 5 2 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>First 1 13 6 2 0 1 0</td>
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</tr>
<tr>
<td>Affective RB</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Third 1 2 1 5 4 3 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 10. Features of Importance Data

<table>
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<th>Not at all Important</th>
<th>Very Unimportant</th>
<th>Neither Important nor Unimportant</th>
<th>Very Important</th>
<th>Extremely Important</th>
</tr>
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<tbody>
<tr>
<td><strong>RB</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>14</td>
<td>10</td>
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<tr>
<td>Ease of use</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>10</td>
<td>14</td>
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<tr>
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<td>0</td>
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<td>Complexity of language</td>
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<td>0</td>
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</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ease of access</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>14</td>
<td>11</td>
</tr>
<tr>
<td>Ease of use</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>Quality of included Evidence</td>
<td>0</td>
<td>2</td>
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<tr>
<td>Source</td>
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<tr>
<td>Format</td>
<td>0</td>
<td>1</td>
<td>8</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>Complexity of language</td>
<td>1</td>
<td>1</td>
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<td>9</td>
<td>10</td>
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<td>9</td>
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</tbody>
</table>
Table 9 presents results for participant indication of recommendation and familiarity, as well as an indication of preference when recommending each CPG for RB and affective symptoms. There was a significant correlation ($r=0.935, p=0.000$) between responding expert preferred CPGs for RB and those preferred for affective symptoms. There was no statistically significant difference between preference answers for RB and affective symptoms ($t(22)=1.279, p=2.15$).

Figure 5. Preference of Clinical Practice Guidelines

A Pearson’s $r$ correlation analysis revealed a statistically significant relationship between the rate of familiarity and rate of recommendations ($r=0.942, p=0.002$). There was a significant correlation ($r=0.919, p=0.003$) between guidelines experts had recommended and their indication of first preference. As shown in Figure 5, the highest preference of guideline was the Behaviour Management: A Guide to Good Practice (24 indications, 16 as first preference) followed by Reducing Behaviours of Concern (ReBOC) guidelines (22 indications, 10 as second preference) and the Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD) A Handbook for NSW Health Clinicians (11 indications, 8 as third preference).

For questions regarding guidelines recommended by experts within the previous six months prior to survey, respondents were given the option to answer Other (Please Specify). Although no other CPGs were identified,
several answers gave insight into alternative formats of resources recommended to assist care staff respond appropriately to RB. The most noted responses included the online DBMAS and AAV Help Sheets (2 indications), the TRACS Quick Reference Cards (3 indications) and the NPS website for medication (2 indications).

**Features of Importance within a Guideline**

*Table 10* displays data for indication of importance for features contributing to recommendations. Results are shown for RB and affective RB. There was a significant correlation \( r=0.982, p=0.000 \) between features contributing to recommending general guidelines for alleviating RB and guidelines specifically for RB involving affective symptoms. There was no statistically significant difference between answers regarding features for RB and affective symptoms \( t(22)=-4.007, p=.007 \).

A One-Way ANOVA found the ranking of features to be significant \( F(13)=12.935, p=0.02 \) suggesting a significant variation in how the features contribute to guideline recommendation. The effect size for this variation was large \( ETA^2=.917 \). Ease of use was ranked as the most important consideration when recommending a CPG for RB. This was followed by content, ease of access, complexity of language, quality of included evidence, format and finally source.

When questioned about features which contribute to recommendations, participants had the option of “Other (Please Specify)”. One participant stated “Online is great but many residential care staff do not have access to computers and if they do printing large book/guideline is difficult. Hardcopies are still requested a lot. Use of Smart Phones and ipads is growing but many facilities in my experience do not have access to tablets/ipads”. Another participant stated, “No cost and comprehensible in a short period of time are most important”.

**Recommendation and Quality**

Correlation of expert recommendations with the iCAHE scores found a non-significant low correlation \( r=0.21, p=.317 \). This suggests experts are not necessarily recommending CPGs based on the same criteria as iCAHE.
assessments. This is evident in Figure 6 which compares iCAHE Score of individual guidelines with their rate of recommendation.

![Graph showing the relationship between recommendation and quality](image)

**Figure 6. Rates of Guidelines Recommendation and Quality Score (iCAHE)**

**Discussion**

To clarify best sources of evidence, this study aimed to investigate expert recommended guidelines, to determine if recommended guidelines are of a suitable quality for practice for the non-pharmacological symptoms of dementia in residential care settings, to identify features of importance when recommending guidelines and if there are variations in recommendation for symptom sub-groups.

Primarily, this research aimed to discover which CPGs experts have recommended and the reasoning behind this recommendation. There was a clear preference for the recommendation of *Behaviour Management: A Guide to Good Practice* which was recommended at least once, and rated within the top three preferred guidelines, by the large majority of participants (96%). Although there seems to be a strong consensus regarding this guideline,
this may be the result of it being developed by the DBMAS who also employed all participants. It is likely that participants were trained to use this guide, encouraged to recommend this guide or even involved in its development. This may have biased the participants. Further, the workplace culture within the DBMAS could affect the uptake of alternative CPGs. Standard practice and the culture of usual practice within an organisation has been found to either be reinforcing EBP or inhibiting it [122]. Given this, it is likely that DBMAS standard policies influence consultant CPG recommendation behaviours and contribute to the high recommendation of the DBMAS guideline. However, despite issues regarding the influence of workplace culture and potential bias this CPG remains a high quality guideline with expert preference and should be recommended above others for care workers seeking guidance.

This research compared expert recommendations with quality assessment of CPGs to determine if expert recommendations are correlated with ‘acceptable’ level of evidence quality as deemed by the iCAHE assessment. Of the seven guidelines identified, only two could be said to be of a ‘high’ level; Behaviour Management: A Guide to good Practice (DBMAS) and the NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care. Over all the guides identified, there was no significant correlation between expert recommendations and the iCAHE scores suggesting discrepancy between this assessment and experts’ recommendations.

The most recommended guide was the DBMAS guide which was also rated as high quality by its iCAHE score. While its popularity may in part be due to its familiarity to the participants the effect of its quality cannot be ruled out. In this vein, familiarity was found to be significantly correlated with likelihood to recommend another guideline, the ReBOC guide, which was rated second for recommendation despite lower iCAHE score as it is also developed by the DBMAS. There was a significant drop from 88% to 28% for the next most popular guideline giving further evidence that familiarity was the key factor influencing guideline recommendation. Ensuring familiarity may be key to the introduction and dissemination of high quality CPGs. Future research and practice should aim towards development and introduction of high quality guidelines to ensure end-users are being familiarised with the highest quality guides to improve care practices.

Another primary aim of this research was the identification of the key features of a guideline which make it a suitable candidate for recommendation. Usability or ‘Ease of Use’ was rated the top feature considered when
recommending a CPG. Usability is defined as when a “user is able to do what he or she wants to do the way he or she expects to be able to do it, without hindrance, hesitation or question” [123]. Usability is especially critical in the design, dissemination and implementation of information such as CPGs [123]. Usability has been described as testing ‘Quality in Use’ with a focus on functionality, reliability, efficiency, maintainability and portability [124]. This finding may be instructive to guideline developers and researchers as it points to the possibility that the next step is not to develop more high quality guidelines, but to increase the usability of existing guides. In this respect, assessing the ‘quality’ of guidelines could identify those with high quality content as candidates for reform using usability research to improve practical application within real world care procedures. In this same light, ‘Content (e.g. identifies appropriate intervention for symptoms, instruction for applying interventions)” was ranked second. These highest ranked features hint towards usability and application. Similarly, ‘Complexity (medical terms or a simple description)” was ranked above ‘Quality (e.g. based on systematic review of RCTs or experiential opinions)” suggesting that a guideline is more useful when it is written in language understandable by users rather than using medical jargon and that this is even more important to users than the quality of the evidence. When questioned about features which contribute to recommending a particular CPG, one participant added a comment regarding access to computers. Although format was ranked 6th, there is the important issue raise here that format dictates accessibility. Although there is a growing focus on digital formats they limit access by staff and thus lower familiarity, which has a higher correlation with recommendation. Perhaps, given the limited access to technologies in many care settings, hard copy guidelines are still the most useful despite issues of being ‘chunky’ and hard to navigate quickly. Another participant raised issues regarding cost and comprehension. Two important ideas are raised; one, that funding many influence access and so cheaper guidelines will be more sort after; and two, that comprehension (both Ease of Use and complexity) need to be prioritised. Guideline developers need to explore options that maximise easy access and usability with end-users.

There was also a very high, statistically significant, correlation between reporting for RB versus affective symptoms. It was hypothesised that recommendation of guidelines would differ when directed towards affective symptoms, however, this was not supported by this research. Participant responding for preference of guideline and features of importance when recommending a guideline had no significant variation for generalised RB to affective-only symptoms. Results suggest that experts did not vary their recommendations based on symptom sub-groups. Although symptom groupings may be useful for diagnostic purposes as dementia progresses and
reflects unique incidences, trajectories, biological correlates, and psychosocial determinants [11], high quality CPGs tended to address individual symptoms rather than cluster groups. It is likely that experts, in line with CPGs, recommend based on RB symptom presentations individually rather than on symptom groups. However, these conclusions are limited by sampling size and scope.

**Limitations and Recommendations**

Although this research reached a 50% response rate of all eligible DBMAS Consultants within Australia, the total number of participants is small. Given this, the power of the calculations is limited and the results should be treated with caution. There was an uneven gender distribution within the sample with large majority of participants being female. Although this is reflective of the female dominated professional backgrounds identified (e.g. nursing, psychology), larger samples would be necessary to eliminate any bias. All participants were from one government funded programme. This organisation was deemed to represent an expert panel by the researchers but does not necessarily represent the totality of experts within this research topic. Further, this organisation also developed the highest ranked CPG and thus it may be that participants had familiarity bias towards this guideline due to continued exposure, encouragement to use internal CPGs or involvement in CPG development. It may also be common and accepted practice to use this guideline and thus increases its recommendation rates. Exploration of alternate sources of expert opinions and CPGs would be advantageous for a more comprehensive exploration. This broader approach could include not only other governmental departments within health and policy but also with care staff within residential care facilities, their managers and with residents directly. Future research working directly with care staff populations would be advantageous in the pursuit of EBP. Repetition of the research with wider recruitment avenues would increase statistical power and reduce organisational and gender bias.

**Conclusion**

Although results from this study have not been definitive, it does provide guidance towards best sources of evidence for practice. The *Behaviour Management: A Guide to good Practice (DBMAS)* is a high quality guideline with expert preference and should be tentatively recommended above others as a starting point for care staff.
With regard to the development of new guidelines, several important topics have been raised.

- Guidelines should aim to include the features ranked as most important by experts (ease of use, appropriate language, content and ease of access primarily) while adhering to the quality standards defined by the relevant bodies and evaluations.

- Familiarity was significantly related to likelihood of recommendation and thus quality guidelines should aim to increase guideline familiarity through dissemination of high quality CPGs in practice.

- Lack of access to technologies, such as iPads and laptops, due to funding issues within facilities suggests that low-cost hard copy format may still be most appropriate.

- Experts were not found to vary recommendations based on symptom subgroups. This is likely a reflection of clinical recommendations being individually altered based on presenting symptom, rather than broader clusters.

The *Behaviour Management: A Guide to good Practice (DBMAS)* can be recommended as a high-quality CPG with expert preference, however, this is done with recognition of limitations in sample, influence of workplace culture and bias. Comparison of quality assessments of CPGs with expert recommendations have enabled the identification of the current best source of evidence to support care staff in the non-pharmacological alleviation of RB.
Chapter 5 –Reflection on the findings and Conclusion

“While trying to be scientific we can often lose sight of the real object of investigation – the person.”
Me, 2018

With the growing ageing population, and associated age-related disease, the translation of dementia research has been called a ‘Global Health Priority’ [1]. The support of staff within residential care facilities through successful translation of evidence based resources allows for quality in practice and the preservation of dignity in care. However, in the absence of clear guidance towards EBP, up to 84% of people with dementia living in RACFs are prescribed medication to relieve RB due to ease of administration and rapid effect [25]–[28]. The level of care needed within RACFs is increasingly complex, yet the ratio of registered nurses to less qualified care staff is diminishing for cost-saving reasons [32]. The delivery of EBP can be enhanced through ongoing support and the provision of easy-to-use research tools such as Clinical Practice Guidelines (CPGs) [35]. Although there is an array of guidelines available to support staff to care for RB, to date there has been a large gap in the literature regarding identification of best evidence, guidance available in choice of guideline and which guidelines facilitate the use of evidence in practice [125]. Knowledge translation (KT) works from the premise that research is of little value without real world application and aims to increase practitioner tendencies to identify and utilise quality research evidence in their practice [39].

This thesis aimed to answer the following research question;

In the context of Knowledge Translation, what is the usefulness of different methods to identify best ‘sources of evidence’ for care staff on the non-pharmacological alleviation of affective Responsive behaviours in dementia?

In response, this research adopted the Outcome-Focused Knowledge Translation Framework (OFKTF) [51] in its KT strategy and aimed to clarify best sources of evidence for the non-pharmacological alleviation of RB in residential care. Specifically, this was achieved through research syntheses, quality and usability appraisal of CPGs and expert opinion as a starting point to evidence-based practice and clarification of care choices. It explored the sequential use of multiple methods to generate clear recommendations for care staff on how to
manage RB symptoms using non-pharmacological approaches. An affective symptom focus was taken in order to limit the scope of the research to manageable proportions and to focus on the most burdensome symptom subgroup [11].

A panoramic meta-analysis aimed to synthesise the available literature on affective symptoms of dementia and the non-pharmacological interventions. However, the study was unable to generate clear recommendations for the non-pharmacological intervention of affective symptoms. This was owing to large heterogeneity and sampling issues within included RCTs or insufficient RCTs to generate power within the calculations. Despite this, this review was able to generate three tentative recommendations indicating the best available interventions for practice; music therapy for anxiety, staff development for depression and person-centred care for aggression. Although other interventions had promise for reducing affective symptoms they did not have adequate statistical power for recommendation in practice. Although panoramic methods were unable to identify best sources of evidence within this research, they do hold potential for fields where there is a more complete data set or where heterogeneity is more controllable.

**Beyond the “platinum standard” in research with people with dementia**

Study 1, in accordance with the ‘platinum standard of evidence’ [61] and primary sources of evidence within the OFKTF [51], included only RCTs in its analysis. However, there are methodological barriers unique to dementia research, such as an inability to control variables, medications, lack of resources or inadequate consideration of the complexity of social and psychological covariates associated with RB [101], [102], [126], [127]. These may negate RCTs and meta-analyses within this field as insufficient. Biomedical models in research have led to narrowness of scope [104] where sub-types of dementia are viewed separately and the complexities of the condition are overlooked [126]. This is despite the fact that the majority of dementias have varying degrees of pathologies [128], accompanying co-morbidity, polypharmacy, individual difference, disease trajectories, measurement of outcomes and cultural and linguistic considerations [126]. The reality is that the homogeneity necessary for successful RCT experimentation may be unobtainable when exploring social or psychological phenomenon and fall short in obtaining external validity – that is, these conclusions can be transferred beyond treatment conditions to clinically applicable external contexts. Further, funding stigmas of qualitative research as ‘soft’ science leaves researchers with no option but to adopt mixed-methods approaches.
that appear viable or ‘scientific’ for external grants [109] often at the cost of meaningful exploration.

Moving away from quantitative rigidity and in light of Study 1 results, best practice hierarchies suggested that when systematic reviews were unable to identify best evidence then ‘evidence based CPGs based on systematic reviews of RCTs’ [52] are the next level in best practice. In concurrence, the OFKTF identified clinical practice guidelines and expert opinion[51], [110] as alternative sources of evidence to support clinical decisions for care staff which guided this research beyond Study 1.

There is an overwhelming amount of evidence to navigate when selecting CPGs for the non-pharmacological care of RB and there is a gap in the current literature regarding guidance towards effective CPGs to clarify best evidence [125]. To address this, Study 2 appraised CPG quality and usability as a source of evidence. It firstly identified which guidelines were available and then assessed quality using the Intervention Centre for Allied Health Evidence (iCAHE) Guideline Quality Checklist. Two of the identified CPGs reached ‘high’ quality; *Behaviour Management: A Guide to good Practice (DBMAS)* and the *NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care*. Although the *NICE-SCIE* was ranked first for quality, it did not represent best evidence due to limitations regarding extensiveness of included symptoms and interventions and usability. The *NICE-SCIE* scored highest on quality of evidence but the *DBMAS* guideline scored higher on usability. Despite being ranked below the *NICE-SCIE* for total iCAHE score, the *DBMAS* guide [78] had a more complete schedule of symptom recommendations and divided evidence into symptom modules for ease of navigation. Usability should be prioritised when assessing CPG quality and deserves more attention in assessment procedures to identify best evidence for KT. Further, this guide is available in hard copy, smartphone application and digital formats to suit all clinician preferences and access [129]. It was designed based on a combination of systematic review, expert consultation and quality assessments and has considerations such as symptom management with CALD and LGBTI populations [129]. Given these factors, the *DBMAS* guide may represent the best source of evidence currently available to promote uptake in care and an appropriate starting point for dissemination strategies.

The assessment of CPG quality using the iCAHE checklist was useful to highlight that the quality of guidelines in this study were limited by search strategies, dissemination of interventions and including a summary of recommendation. Guidelines researchers and developers are encouraged to rectify these shortcomings in future
versions and in the development of new guidelines. This method was able to identify two high quality CPGs, however, its ranking of quality did not support the identification of best evidence as the DBMAS guide, which is more complete in its dissemination of RB interventions and is more usable by care staff, was ranked below the NICE-SCIE. Although it is necessary to assess the methodological quality of guidelines to ensure credibility [112], critical appraisal of CPG quality as a source of evidence within the OFKTF in isolation is unlikely to be sufficient to direct guideline selection, especially in regards to CPG usability. The OFKTF suggested that a logical progression in this research was to assess expert opinion to compare how clinicians recommendations of guidelines varies from quality assessments [51], [110] and to investigate how experts weigh factors of quality and usability when recommending CPGs for alleviation of RB in RACFs. In a search for best sources of evidence for the non-pharmacological care of RB, study 3 surveyed a panel of experts on their use and recommendation of CPGs. Results were able to give indication towards factors important to experts in guideline selection. Despite limitations regarding familiarity bias, the Behaviour Management: A Guide to good Practice (DBMAS) was found to be a high-quality guideline with expert preference and could be the best starting point for care staff searching CPGs in their care of RB. This survey gave indication that ease of use, appropriate language, content and ease of access should be focus when developing new CPGs. This should be done in conjunction with quality assessments and in hard copy format. Within the literature, the tendency is to promote digital formats that “provide electronic decision support prompts at the point of choice” (p.117, [130]) due to their ability to communicate rapidly, provide feedback and encourage greater adherence to EBP [130], [131]. However, access to the internet and digital devices is limited in most RACFs and negate the appropriateness for digital copies to promote EBP. Lack of familiarity has been found to hinder the adoption of resources within healthcare [132] and thus future KT endeavours would benefit from focus on increasing care staff familiarity with quality evidence to promote EBP.

Contrary to expectations, recommendations did not alter for affective symptoms. It was thought that each subgroup would vary due to individual difference, symptom trajectories, biological correlates, and psychosocial determinants [11]. However, this was not found within the current research. Analysis of survey data allowed comparison of quality assessment with expert opinion to reveal one high-quality CPG with expert recommendation as the best currently available source of evidence for RB intervention. Both organisational bias and workplace practices [122] were likely influencers of the preference for the DBMAS guide in this study as experts may be more influenced by these familiarity biases than by current evidence. Yet despite this, the
DBMAS guide may represent the current best source of evidence and may be a logical starting point for dissemination strategies to direct care staff towards EBP. In this, it was the combination of the three methods that was most useful able to identify best source of evidence to support care staff in the non-pharmacological alleviation of RB in dementia.

Despite a large amount of available literature and guidelines addressing RB, to date there has been a large void in guidance available to direct care staff care decision and assessment of which methods promote EBP [125]. Studies 1 and 2 within this research concluded that the methods utilised were only able to generate tentative recommendations for RB intervention. Study 3, although limited by itself, was able to use findings from study 2 in combination with survey methods to identify one high-quality CPG for RB intervention. Despite limitations in all phases of this research, when viewed over all three studies there is quite a lot of evidence generated in the exploration of synthesis methods to identify best sources of evidence. This research found the following;

- Three statistically significant symptom by intervention combinations; music therapy for anxiety, staff development for depression and person-centred care for aggression
- Three CPGs deemed acceptable quality
- Two CPGs deemed high quality
- One guideline of high quality with expert preference; Behaviour Management: A Guide to good Practice (DBMAS)

Further, it was able to give clear directions towards future research endeavours.

- Increase power of calculations by additional RCTs and meta-analyses
- Improve the quality of current and future CPGs
- Review and development of CPGs should focus on ease of use, appropriate language, content and ease of access in conjunction with quality assessments in hard copy format.
- Methods to increase familiarity of experts and care staff with existing high quality CPGs
Table 11. Comparison of DBMAS guideline with Panoramic Review

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<tr>
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<th>DBMAS</th>
<th>Panoramic Methods</th>
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<tr>
<td>Aggression</td>
<td>Individualised psychosocial interventions*, some support for light massage, individual behavioural therapy*, bright light therapy and Montessori activities</td>
<td>Person-Centred Care Approaches*</td>
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<tr>
<td></td>
<td></td>
<td>Multi Sensory Stimulation</td>
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<tr>
<td>Agitation</td>
<td>Music therapies*</td>
<td>Multi Sensory stimulation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(including Snoezelen)*</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Multicomponent interventions which target environmental, biological and psychosocial factors contributing to anxiety. Some evidence for music*, Montessori, and psychotherapies.</td>
<td>Music therapy*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Multi Sensory Stimulation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(including Snoezelen)</td>
</tr>
<tr>
<td>Apathy</td>
<td>Therapeutic recreation using “question-asking reading”, small group, individual/tailored, Montessori based and kit-based activities.</td>
<td>Multi Sensory stimulation</td>
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<tr>
<td></td>
<td></td>
<td>(including Snoezelen)</td>
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<td></td>
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<td>Light Therapy</td>
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<tr>
<td>Depression</td>
<td>Exercise and behavioural approaches*</td>
<td>Staff development</td>
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<td></td>
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<td>Reminiscence Therapy</td>
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<tr>
<td></td>
<td></td>
<td>Behavioural interventions*</td>
</tr>
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</table>

*Overlapping conclusions

Table 11 allows a comparison of the Panoramic review from Study 1 with the care options within the CPG identified as best in Study 2 and 3. There has been some key cross over in findings. Aggressive symptoms have been alleviated by PCC and has some evidence for Sensory based interventions (e.g. music, massage). Similarly,
sensory based interventions were supported for agitation and anxiety with stronger evidence for Music Therapy specifically. Behavioural interventions for depression were supported across studies. These overlapping interventions may be key in determining where the best evidence lies and where to focus attention to clarify care choices for RB.

Perhaps each method, although insufficient in isolation, contributes to the larger picture. The outcomes from these studies beg the question; can any one method of enquiry such as meta-analyses or survey be held as the ‘platinum’ evidence base for studying complex topics such as RB and other dementia-related conditions? Study 1 followed a purely quantitative approach which debated the RCT as the gold standard in research. Although this method holds promise for research topics with more complete literature, in the case of RB it was limited. The heterogeneity within social and psychological phenomenon such as when investigating populations with dementia may render the RCT unable to reach internal or external validity needed in these demographics. These investigations are often narrowed in scope by excluding comorbidities, CALD populations or those in advanced stages of the disease to appear ‘scientific’ and homogeneous often at the cost of meaningful exploration. This exclusion can diminish the dignity of those with dementia to the status of object of study and the disregard the personal, psychological and social facets unique to diseases such as dementia. The identified guidelines from Study 2 mimicked this RCT gold standard debate. They focused more on source and incorporation of RCTs than on real world usability. This is despite the fact that experts deemed usability as the most critical component for guideline recommendations. Further, a purely quantitative rank system of quality assessments did not identify best sources of evidence. A step away from the quantitative standards in Study 3 led to the identification of Behaviour Management: A Guide to good Practice (DBMAS) as an expert recommended CPG. Referring back to quality assessments in Study 2 revealed that this guide, although ranked second, is the best available option to clarify RB care options for care staff. Further comparison of this guideline with results from quantitative panoramic methods allows for specific recommendations for research and practice. This mixed approach gives weight to the notion that the research into psychological and social determinant are critical when studying human phenomenon [109]. Quantitative research, which gives the appearance of being ‘scientific’ and is more appealing to funding bodies, is at the forefront of research into social behaviours and psychological phenomenon in dementia, yet this is not logical [102]. This is not to say, however, that quantitative research is not required but rather that often incorporation of qualitative methods, or mixed methods, are required when humans are involved [109]. Despite quantitative ‘answers’, these must be subject to external validity testing and
validation through real world intervention to have meaning [102]. In the case of guidelines, this testing would logically be through the examination of usability and resident outcomes. Usability is a theme that continually presented itself throughout this research. It is essential within Knowledge Translation research as there is little value in evidence without external validity, or real world application [39], [49].

### Conclusion

In time constrained RACFs, care staff require guidance towards quality sources of evidence that facilitate Evidence Based Practice (EBP) in the alleviation of RB. This thesis followed the OFKTF to identify sources of evidence for non-pharmacological management of RBs through a sequential mixed methods study investigating quantitative research syntheses, Clinical Practice Guidelines (CPGs) and expert opinion as a starting point to EBP. Quantitative panoramic analyses were unable to identify best evidence due to large heterogeneity and sampling issues within included RCTs or insufficient RCTs to generate power within the calculations. Given this, alternative methods exploring expert opinion, quality and useability of CPGs were needed to determine best evidence for the generation of care recommendations. Quality assessment and survey of experts on recommendation of CPGs identified the Behaviour Management: A Guide to good Practice (DBMAS) guide as a high quality guideline with expert preference and could be the best starting point for care staff using CPGs in their care of RB. Recommendations did not alter for affective symptoms.

Definitively clear recommendations were not found by any one method within this research but rather through a cumulative effect of mixed methods. With regards to the RQ, the studies undertaken were useful to highlight that different methods (research synthesis, analysis of guideline quality and expert preference), while insufficient in isolation, were useful together to identify best ‘sources of evidence’ for non-pharmacological alleviation of affective Responsive behaviours in dementia.
References


[122] K. Manley, K. Sanders, S. Cardiff, and J. Webster, *Effective workplace culture: the attributes, enabling


Appendices

Appendix A - Search Strategy

Step 1: Preliminary search.

This step involved a preliminary search of MEDLINE and CINAHL databases using the following keywords;

Keywords

- Dementia
- Alzheimer*
- systematic review
- meta-analysis
- Neuropsychiatric
- Non-cognitive
- Psycholog*
- Behav*
- BPSD
- Affective
- Depression
- Anxiety
- Agitation
- Aggression
- Apathy

Step 2: Extract additional keywords.

Titles, abstracts, keywords and indexes from relevant articles within the preliminary search were examined. Any additional keywords found were added for the focal search.

Step 3: Systematic search

Systematic searches of JBI, Scopus, Cochrane, PubMed, Medline, PROSPERO, Epistemonikos and CINAHL databases will be conducted. Database specific search fields will be applied within each search. Additionally, reference lists for included reviews will be examined manually.

The search for unpublished studies will include, but not be limited to the following:

- Dissertation abstracts
- Australian Government and initiatives websites
- Research institutes in the area; eg. The Dementia Behaviour Management Advisory Scheme (DBMAS) and Alzheimer’s Australia

Keywords

- Dementia
Dementia OR Alzheimer*

AND

Systematic review OR meta-analysis

AND

neuropsychiatric OR BPSD OR behav* OR psycholog* OR non-cognitive OR affect* OR anxi*OR agitat* OR depress* OR aggress* OR apath* OR irritability OR mood OR dysphor*

MeSH: dementia, Alzheimer Disease, systematic review, meta-analysis, psychology, psychological tests, affective symptoms, anxiety, aggression, depression, apathy, affect, irritable mood
Appendix B - Search Strategy for Guideline Selection

Step 1: Preliminary search.
This step involved a preliminary search of MEDLINE and CINAHL databases using the following keywords:

- Dementia
- Alzheimer*
- Guid*
- Clinical
- Manag*
- Practice
- Consensus
- Neuropsychiatric
- Non-cognitive
- Psycholog*
- Behav*
- BPSD
- Affective
- Depression
- Anxiety
- Agitation
- Aggression
- Apathy

Step 2: Extract additional keywords.
Titles, abstracts, keywords and indexes from relevant articles within the preliminary search were examined. Any additional keywords found were added for the focal search.

Step 3: Systematic search
Systematic searches of Scopus, Cochrane, PubMed, Medline, EMBASE, CINAHL databases will be conducted.

Database specific search fields will be applied within each search. Additionally, reference lists for included reviews will be examined manually.

The search for unpublished studies will include, but not be limited to the following:

- Dissertation abstracts
- Australian Government and initiatives websites
- Research institutes in the area; eg. The Dementia Behaviour Management Advisory Scheme (DBMAS) and Alzheimer’s Australia and the National Health and Medical Research Council (NHMRC) Clinical Practice Guidelines Portal.
- Google and Google Scholar search engines were searched using the search terms ‘dementia’ and ‘guidelines’. All results were scanned for relevance.
Keywords

Dementia OR Alzheimer*

AND

Guid* OR clinical OR Manag* OR practice OR consensus

AND

neuropsychiatric OR BPSD OR behav* OR psycholog* OR non-cognitive OR affect* OR anxi* OR agitat* OR depress* OR aggress* OR apath* OR irritab* OR mood

MeSH: dementia, Alzheimer Disease, practice guideline, psychology, affective symptoms, anxiety, aggression, depression, apathy, affect, irritable mood
Appendix C – AMSTAR

**AMSTAR – a measurement tool to assess the methodological quality of systematic reviews.**

1. **Was an 'a priori' design provided?**
   - The research question and inclusion criteria should be established before the conduct of the review.
   - Yes
   - No
   - Can't answer
   - Not applicable
   - Note: Need to refer to a protocol, ethics approval, or pre-determined/a priori published research objectives to score a "yes."

2. **Was there duplicate study selection and data extraction?**
   - There should be at least two independent data extractors and a consensus procedure for disagreements should be in place.
   - Yes
   - No
   - Can't answer
   - Not applicable
   - Note: 2 people do study selection, 2 people do data extraction, consensus process or one person checks the other's work.

3. **Was a comprehensive literature search performed?**
   - At least two electronic sources should be searched. The report must include years and databases used (e.g., CENTRAL, EMBASE, and MEDLINE). Key words and/or MESH terms must be stated and where feasible the search strategy should be provided. All searches should be supplemented by consulting current contents, reviews, textbooks, specialized registers, or experts in the particular field of study, and by reviewing the references in the studies found.
   - Yes
   - No
   - Can't answer
   - Not applicable
   - Note: If at least 2 sources + one supplementary strategy used, select "yes" (Cochrane register/Central counts as 2 sources; a grey literature search counts as supplementary).

4. **Was the status of publication (i.e. grey literature) used as an inclusion criterion?**
   - The authors should state that they searched for reports regardless of their publication type. The authors should state whether or not they excluded any reports (from the systematic review), based on their publication status, language etc.
   - Yes
   - No
   - Can't answer
   - Not applicable
   - Note: If review indicates that there was a search for "grey literature" or "unpublished literature," indicate "yes." SIGLE database, dissertations, conference proceedings, and trial registries are all considered grey for this purpose. If searching a source that contains both grey and non-grey, must specify that they were searching for grey/unpublished lit.

5. **Was a list of studies (included and excluded) provided?**
   - A list of included and excluded studies should be provided.
   - Yes
   - No
   - Can't answer
   - Not applicable
   - Note: Acceptable if the excluded studies are referenced. If there is an electronic link to the list but the link is dead, select "no."

6. **Were the characteristics of the included studies provided?**
   - In an aggregated form such as a table, data from the original studies should be provided on the participants, interventions and outcomes. The ranges of characteristics in all the studies analyzed e.g., age, race, sex, relevant socioeconomic data, disease status, duration, severity, or other diseases should be reported.
   - Yes
   - No
   - Can't answer
   - Not applicable
   - Note: Acceptable if not in table format as long as they are described as above.
7. Was the scientific quality of the included studies assessed and documented?

'A priori' methods of assessment should be provided (e.g., for effectiveness studies if the author(s) chose to include only randomized, double-blind, placebo controlled studies, or allocation concealment as inclusion criteria); for other types of studies alternative items will be relevant.

Note: Can include use of a quality scoring tool or checklist, e.g., Jadad scale, risk of bias, sensitivity analysis, etc., or a description of quality items, with some kind of result for EACH study ("low" or "high") is fine, as long as it is clear which studies scored "low" and which scored "high"; a summary score/range for all studies is not acceptable.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Can't answer</th>
<th>Not applicable</th>
</tr>
</thead>
</table>

8. Was the scientific quality of the included studies used appropriately in formulating conclusions?

The results of the methodological rigor and scientific quality should be considered in the analysis and the conclusions of the review, and explicitly stated in formulating recommendations.

Note: Might say something such as "the results should be interpreted with caution due to poor quality of included studies." Cannot score "yes" for this question if scored "no" for question 7.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Can't answer</th>
<th>Not applicable</th>
</tr>
</thead>
</table>

9. Were the methods used to combine the findings of studies appropriate?

For the pooled results, a test should be done to ensure the studies were combinable, to assess their homogeneity (i.e., Chi-squared test for homogeneity, I²). If heterogeneity exists a random effects model should be used and/or the clinical appropriateness of combining should be taken into consideration (i.e., is it sensible to combine?).

Note: Indicate "yes" if they mention or describe heterogeneity, i.e., if they explain that they cannot pool because of heterogeneity/variability between interventions.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Can't answer</th>
<th>Not applicable</th>
</tr>
</thead>
</table>

10. Was the likelihood of publication bias assessed?

An assessment of publication bias should include a combination of graphical aids (e.g., funnel plot, other available tests) and/or statistical tests (e.g., Egger regression test, Hedges-Orken).

Note: If no test values or funnel plot included, score "no". Score "yes" if mentions that publication bias could not be assessed because there were fewer than 10 included studies.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Can't answer</th>
<th>Not applicable</th>
</tr>
</thead>
</table>

11. Was the conflict of interest included?

Potential sources of support should be clearly acknowledged in both the systematic review and the included studies.

Note: To get a "yes," must indicate source of funding or support for the systematic review AND for each of the included studies.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Can't answer</th>
<th>Not applicable</th>
</tr>
</thead>
</table>


Additional notes (in italics) made by Michelle Weir, Julia Worswick, and Carolyn Wayne based on conversations with Bev Shea and/or Jeremy Grimshaw in June and October 2008 and July and September 2010.

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## Appendix D- JBI Data Extraction Form for Review for Systematic Reviews and Research Syntheses

### JBI Data Extraction Form for Review for Systematic Reviews and Research Syntheses

<table>
<thead>
<tr>
<th>Study Details</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Author/year</td>
<td></td>
</tr>
<tr>
<td>objectives</td>
<td></td>
</tr>
<tr>
<td>Participants (characteristics/total number)</td>
<td></td>
</tr>
<tr>
<td>Setting/context</td>
<td></td>
</tr>
<tr>
<td>Description of Interventions/phenomena of interest</td>
<td></td>
</tr>
</tbody>
</table>

### Search Details

| Sources searched |  |
| Range (years) of included studies |  |
| Number of studies included / |  |
| Types of studies included |  |
| Country of origin of included studies |  |

### Appraisal

| Appraisal instruments used |  |
| Appraisal rating |  |

### Analysis

| Method of analysis |  |
| Outcome assessed |  |
| Results/Findings |  |
| Significance/direction |  |
| Heterogeneity |  |

### Comments

|  |  |
# Appendix E - The Intervention Centre for Allied Health Evidence (iCAHE) Guideline Quality Checklist

## iCAHE Guideline Quality Check List

**Guideline:**

**Guideline producer:**

**Link:**

<table>
<thead>
<tr>
<th>Availability</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the guideline readily available in full text?</td>
<td>(1)</td>
</tr>
<tr>
<td>Does the guideline provide a complete reference list?</td>
<td>(1)</td>
</tr>
<tr>
<td>Does the guideline provide a summary of its recommendations?</td>
<td>(1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there a date of completion available?</td>
</tr>
<tr>
<td>Does the guideline provide an anticipated review date</td>
</tr>
<tr>
<td>Does the guideline provide dates for when literature was included?</td>
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</table>

<table>
<thead>
<tr>
<th>Underlying Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the guideline provide an outline of the strategy they used to find underlying evidence?</td>
</tr>
<tr>
<td>Does the guideline use a hierarchy to rank the quality of the underlying evidence?</td>
</tr>
<tr>
<td>Does the guideline appraise the quality of the evidence which underpins its recommendations?</td>
</tr>
<tr>
<td>Does the guideline link the hierarchy and quality of underlying evidence to each recommendation?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Guideline developers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are the developers of the guideline clearly stated?</td>
</tr>
<tr>
<td>Does the qualifications and expertise of the guideline developer(s) link with the purpose of the guideline and its end users?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Guideline purpose and users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are the purpose and target users of the guideline stated?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ease of use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the guideline readable and easy to navigate?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Score</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>/14</td>
</tr>
</tbody>
</table>

---

International Centre for Allied Health Evidence (iCAHE)
City East Campus, North Tce, Adelaide
University of South Australia
### Appendix F - PRISMA 2009 Checklist

#### PRISMA 2009 Checklist

<table>
<thead>
<tr>
<th>Section/Topic</th>
<th>Checklist item</th>
<th>Reported on page #</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TITLE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Title</td>
<td>Identify the report as a systematic review, meta-analysis, or both.</td>
<td></td>
</tr>
<tr>
<td><strong>ABSTRACT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structured summary</td>
<td>Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria; participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.</td>
<td></td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rationale</td>
<td>Describe the rationale for the review in the context of what is already known.</td>
<td></td>
</tr>
<tr>
<td>Objectives</td>
<td>Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICO/S).</td>
<td></td>
</tr>
<tr>
<td><strong>METHODS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protocol and registration</td>
<td>Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.</td>
<td></td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.</td>
<td></td>
</tr>
<tr>
<td>Information sources</td>
<td>Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.</td>
<td></td>
</tr>
<tr>
<td>Search</td>
<td>Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.</td>
<td></td>
</tr>
<tr>
<td>Study selection</td>
<td>State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).</td>
<td></td>
</tr>
<tr>
<td>Data collection process</td>
<td>Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.</td>
<td></td>
</tr>
<tr>
<td>Data items</td>
<td>List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.</td>
<td></td>
</tr>
<tr>
<td>Risk of bias in individual studies</td>
<td>Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.</td>
<td></td>
</tr>
<tr>
<td>Summary measures</td>
<td>State the principal summary measures (e.g., risk ratio, difference in means).</td>
<td></td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I²) for each meta-analysis.</td>
<td></td>
</tr>
</tbody>
</table>
### PRISMA 2009 Checklist

<table>
<thead>
<tr>
<th>Section/Topic</th>
<th>#</th>
<th>Checklist Item</th>
<th>Reported on page #</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk of bias across studies</td>
<td>15</td>
<td>Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).</td>
<td></td>
</tr>
<tr>
<td>Additional analyses</td>
<td>16</td>
<td>Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.</td>
<td></td>
</tr>
<tr>
<td><strong>RESULTS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study selection</td>
<td>17</td>
<td>Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.</td>
<td></td>
</tr>
<tr>
<td>Study characteristics</td>
<td>18</td>
<td>For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.</td>
<td></td>
</tr>
<tr>
<td>Risk of bias within studies</td>
<td>19</td>
<td>Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).</td>
<td></td>
</tr>
<tr>
<td>Results of individual studies</td>
<td>20</td>
<td>For all outcomes considered (benefit or harm), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.</td>
<td></td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>21</td>
<td>Present results of each meta-analysis done, including confidence intervals and measures of consistency.</td>
<td></td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>22</td>
<td>Present results of any assessment of risk of bias across studies (see item 15).</td>
<td></td>
</tr>
<tr>
<td>Additional analysis</td>
<td>23</td>
<td>Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see item 16]).</td>
<td></td>
</tr>
<tr>
<td><strong>DISCUSSION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summary of evidence</td>
<td>24</td>
<td>Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).</td>
<td></td>
</tr>
<tr>
<td>Limitations</td>
<td>25</td>
<td>Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).</td>
<td></td>
</tr>
<tr>
<td>Conclusions</td>
<td>26</td>
<td>Provide a general interpretation of the results in the context of other evidence, and implications for future research.</td>
<td></td>
</tr>
<tr>
<td><strong>FUNDING</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funding</td>
<td>27</td>
<td>Describe sources of funding for the systematic review and other support (e.g., supply of data), role of funders for the systematic review.</td>
<td></td>
</tr>
</tbody>
</table>


For more information, visit [www.prisma-statement.org](http://www.prisma-statement.org)

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