



The Dementia Health Literacy Intervention For Informal Caregivers: A Systematic Review Protocol

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ABSTRACT

This review will systematically examine the effectiveness of educational interventions on dementia health literacy (DHL) among informal caregivers (ICs) in 42 Asia Pacific countries/territories. Methods: A systematic literature search will be performed in nine databases. No date nor language restriction will be applied. The quality of studies will be assessed using existing appraisal tools (i.e. Joanna Briggs Institute's Checklists) and an inductive narrative synthesis technique will be used to analyse the extracted data. Randomized Controlled Trial (RCT) and non-RCT interventions will be full-reviewed but only RCT studies will be pooled in a meta-analysis. Heterogeneity, publication bias, and sensitivity will also be assessed. Results: The results will be reported following the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) 2020 statement. The standardized procedure and reporting will ensure the review's quality and could be used by the stakeholders in the region for planning DHL-related programs and significantly contribute to dementia caregiving and caregiver literature and programs. Conclusion: This protocol of the planned systematic review and meta-analysis of the effectiveness of educational interventions on DHL for ICs in the Asia Pacific countries/territories will set the foundation for its further progress.

Keywords: Aging, Alzheimer's, Caregiving, Gerontology, Global South

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INTRODUCTION

Dementia is one of the chronic neurodegenerative diseases, characterised by a progressive and irreversible decline in cognitive functions, including memory, orientation, comprehension, language,

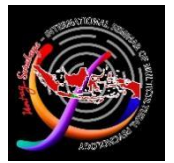
and judgement that mainly affects older adults (Lam et al., 2019; WHO, 2021). Currently, dementia is one of the leading causes of death among all diseases and the major cause of disability and dependency among older people, which will also put a challenge on the country's healthcare system (Chan et al., 2019; Griffiths et al., 2020; Lam et al., 2019). There are several forms of dementia, of which the commons are Alzheimer's, Vascular Dementia, and Lewy Body Dementia (WHO, 2017). The biggest risk factor for developing dementia is age, as evidenced by the worldwide prevalence increased in line with progressing number of the ageing population (Chan et al., 2019; Wilesmith & Major, 2020). The global dementia estimation from the WHO is approximately 55 million people (WHO, 2021) or 667 cases per 100,000 persons in 2019 (Javaid et al., 2021). This number is predicted to rise to 83 million by 2030, most will live in Asia and Pacific countries (Frias et al., 2020; Hinton et al., 2019; Nichols et al., 2022). In responding to this critical situation, the WHO endorsed dementia as one of the public health priorities because of the global impacts of this disease (WHO, 2017).

The current estimated number of dementia might be obscured by stigma toward dementia, particularly in low-and-middle-income countries (LMICs) spread across the Asia Pacific region (Griffiths et al., 2020; Nichols et al., 2022), which discourages the family from talking about it or seeking help and support when the person is showing dementia symptoms (Goodson et al., 2021; Idura et al., 2018; Rosli et al., 2021; WHO, 2021). The family of people with dementia (PwD) or even the PwD themselves may feel shame about their conditions and withdraw from their community to maintain the family's reputation, which consequently makes the prognosis poor (Gilbert et al., 2021). The condition might be unintentionally observed by the clinicians when the informal caregivers (ICs) were bringing the PwD for other medical concerns and it was already severe (Goodson et al., 2021).

At this moment, dementia has no cure so the focus of treatment is on early diagnosis to delay functional deterioration and behavioural alteration, maintain the quality of life PwD, and improve survival rates of the PwD (Lam et al., 2019; C. W. Leung et al., 2020; WHO, 2021). Dementia does not only affect the person's physical, psychological, social, and economic aspects but also their family and community (WHO, 2021). Therefore, a home-and-person-centred care strategy is preferred in caring for PwD (Clemmensen et al., 2020; Yoon & Kim, 2020) as this strategy could also delay institutionalisation and save the cost of national health services and hidden cost from the loss in productivity for economics (Tey et al., 2016; WHO, 2017).

Providing care for aged parents or older relatives is also a manifestation of filial piety and *sewa* (service), which are cultural values and social norms in Asian communities (Aman et al., 2020; Ramli et al., 2021; Wilson et al., 2021). This home caring strategy is also socially expected in a couple's life to look after a partner with chronic conditions like dementia (Kong et al., 2021; Zubaidi et al., 2020). Furthermore, this family-based care system continues to be the main choice despite the existence of some related policies and guidelines because of the gap in both workforce capacity and capability (i.e. very limited numbers of gerontologists and gerontology clinics) (Goodson et al., 2021; Leng et al., 2016; Ramli et al., 2021).

However, this in-home care strategy also comes with its costs, especially for the ICs of PwD without specific caregiving knowledge and skills, which are considered as part of dementia health literacy (DHL) (Kong et al., 2021; Rosli et al., 2021). ICs with inadequate DHL also tend to feel frustrated because of their unreasonable expectation and beliefs toward PwD (Zulkifley et al., 2020). Previous studies in other Asian countries like Korea and China consistently found that dementia caregivers experienced distress, depression, decreased wellbeing and quality of life due to physical, psychological, and social exhaustion related to caregiving experience (Jia et al., 2020; Wang et al., 2021; Yoon & Kim, 2020). Moreover, ICs could live with the impact of caregiving and loss productivity for up to seven years on average when caring for PwD and facing their behavioural and



psychological symptoms (Bessey & Walaszek, 2019; Gao et al., 2021).

It was consistently found that timely detection and identification of dementia symptoms at home is critical for maximum effects in delaying cognitive decline and behavioural alteration, as well as improving survival rates of the person through practical information, resources/services, and support (Lam et al., 2019; C. W. Leung et al., 2020). Moreover, the early diagnosis was also found to reduce ICs' stress, anxiety, and depression, as well as improved the care provided to the PwD and lowered the medical costs associated with this disease. Therefore, to improve dementia awareness and literacy among ICs, which were found to be highly correlated with better home care (Lam et al., 2019; C. W. Leung et al., 2020), various educational intervention studies (i.e. psychoeducation) had been launched that targeted the spouse or child of older adults with dementia in Asia (Hinton et al., 2019). These interventions could include a single or multiple components (e.g. introduction to dementia and caregiver skill-building) that significantly improved not only caregivers' dementia awareness and literacy but also their quality of life and wellbeing (Hinton et al., 2019). Through the intervention, the ICs could understand and cope better with the problem behaviours and cognitive impairment among PwDs as well as decrease caregiving impact, including distress and depressive symptoms (Cheng et al., 2019).

A review of available educational interventions will enable the identification of the most effective intervention for increasing outcomes related to DHL (e.g. knowledge and attitudes towards dementia), particularly for ICs. It will also assist primary prevention by identifying the strategies to be used among ICs. Previous studies have partially addressed this need but with limitations. For example, one study systematically reviewed the impact of dementia literacy interventions but only included English full-text articles that limited the search and synthesis (Nguyen et al., 2021). Another study did a scoping review on a related topic, which was an evaluation of dementia knowledge assessment instruments utilized in educational programs and interventions (Resciniti et al., 2020). This review found that the majority of dementia awareness and knowledge instruments were validated in high-income countries and the Global North part (i.e. the USA) and the participants were predominantly formal caregivers. Two reviews on dementia caregiving interventions for ICs were limited to family members only, particularly families in Asia (Hinton et al., 2019) and Chinese families globally (Ma & Saw, 2020), which ICs could also be PwD's friends and neighbours. However, domestic workers who are originally hired to do the household tasks (e.g. cooking and cleaning) and have no caregiving knowledge or skills are often also asked to care for older adults without additional pay, which could also make them recognised as ICs (Liem et al., 2021). In addition, sociocultural factors should be considered when developing an intervention plan, which programs in Asian countries might not be suitable for people in Pacific countries due to the differences in culture and health-care system (Cheng et al., 2019; Gilbert et al., 2021). Besides these geographical, cultural, and restricted community limitations, the review was conducted in 2018 that DHL interventions for ICs could increase substantially in the last couple of years.

The current study

Since no single definition of DHL, this current study followed the WHO's definition of health literacy (WHO, 2019) and adopted previous reviews (A. Y. M. Leung et al., 2020; Nguyen et al., 2021) by defining DHL as the capacity of individuals, families, and communities to access, understand, evaluate, and apply dementia-related information in order to make judgements and take decisions in everyday life concerning dementia-related health care, prevention, and health promotion to maintain and/or improve their quality of life. This timely study will systematically review the

available educational interventions on DHL and their effectiveness for ICs’ to access, understand, evaluate, and apply dementia-related information in the Asia Pacific region as the primary outcome. Some examples of the primary outcomes are knowledge and awareness of dementia, help-seeking intention and behaviours regarding dementia, and caregiving skills. The secondary outcomes will cover ICs’ beliefs and attitudes toward dementia and PwD.

The dementia-related information broadly covers recognizing the risk factors and symptoms, knowing the prevention methods and symptoms management, identifying available resources and treatment options, and providing essential care and support to PwD. Following the definition of DHL, these dementia-related information aspects would empower the ICs to translate this knowledge into attitude, beliefs, and actions related to dementia cause, diagnosis, treatment, and caregiving practice(Choi et al., 2018; A. Y. M. Leung et al., 2020; Nguyen et al., 2021). The educational interventions are broadly defined as active actions of any form that are conducted in any platform and setting to improve DHL. The population of interest in this study are ICs who are defined as non-professional individuals (e.g. spouse, child, relative, friend, neighbour, and domestic worker) responsible for PwD care. The research question that will be systematically addressed is “how effective are educational interventions on dementia health literacy for ICs of PwD in the Asia Pacific?”

METHODS

The planned systematic review and meta-analysis will be preregistered at the preprint service for the psychological sciences (PsyArxiv) and the International Prospective Register of Systematic Reviews (PROSPERO). The reporting will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA) 2020 statement (Page et al., 2021). The steps of the search and review are described below.

Search strategies

Peer-reviewed published literature will be systematically searched in five databases (EMBASE, PubMed, PsycINFO, CINAHL, and Cochrane Library) with no date and language restriction. Search strategies for each database can be found in the Supplements. Grey literature and unpublished reports will be identified through four electronic sources (ProQuest Central, Web of Science, OpenGrey, and Google Scholar). Hand-searching will be conducted on the reference lists of included articles and previous related reviews. The first author (AL), who holds a doctoral degree in psychology and works on migration issues, will develop the protocol with intense discussion with the senior authors who are experts in health literacy, global mental health, migration, neurodegenerative diseases, and caregiving (YMS, SV, PR, MPT, TTS). All searches will be performed by AL and two research assistants (RAs) in consultation with the senior authors.

Inclusion and exclusion criteria

The inclusion and exclusion criteria are presented in Table 1 below. The parameter is set in the Asia Pacific region that includes 42 countries and territories (Supplement 1) following the United Nation’s classification (<https://www.ohchr.org/en/countries>). The novelty and significance of this systematic review will be supported by the multiple languages inclusion criterion that is widely used in the region. Only intervention studies will be included.

Table 1. Inclusion and exclusion criteria for systematic review

Aspects	Inclusion criteria	Exclusion criteria
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Areas of focus	of dementia health literacy and equivalent terms (i.e. dementia awareness)	Other than dementia health literacy
Population of interest	Informal caregivers in the Asia Pacific countries and territories	Non-informal caregivers in the Asia Pacific countries; Asia Pacific informal caregivers outside Asia Pacific countries and territories
Language	All languages	None
Types of literature study	Intervention studies; primary studies and secondary data analysis; reviewed and non-reviewed; published and non-published; quantitative, qualitative, and mixed- methods	Literature review; non-research publications (e.g. Government's policy, discussion paper, book review, commentary, and correspondence); duplication from higher-quality literature (e.g. non- published thesis and conference proceeding were excluded if original peer-reviewed articles were available); Non-intervention studies
Text availability	The abstract was available	The abstract was not available

Outcomes

The primary outcome of this study will be ICs' capacity to access, understand, evaluate, and apply dementia-related information, which broadly covers its risk factors, causes, symptoms, assessments, prevention methods, symptoms management, and treatment options. The secondary outcomes will focus on beliefs and attitudes toward dementia and PwD.

Data screening and selection

The first author and RAs will independently screen titles and abstracts identified in the search. Screened articles will then independently be reviewed in full by the same reviewers following the inclusion and exclusion criteria. The total inter-rater score will be calculated. Any disagreement will be discussed until consensus is reached and articles that needed further examination are discussed with the senior authors. Team members will communicate regularly to discuss every step of this study selection process.

Quality assessment

The qualitative and quantitative studies' quality will be assessed using two appraisal tools from the Joanna Briggs Institute: Checklist for Qualitative Research Skills (Lockwood et al., 2015) and Checklist for Analytical Cross-Sectional Studies (Moola et al., 2017). The mixed-methods studies' quality will be evaluated using the 3-point criteria of the Mixed-Methods Appraisal Tool (MMAT) (Pluye et al., 2011). Grey literature will be assessed with the Authority, Accuracy, Coverage, Objectivity, Date, Significance (AACODS) Checklist (Tyndall, 2010) that covers authority, accuracy, coverage, objectivity, date, and significance. The quality assessment will be performed by

two authors (AL, YMS). The total inter-rater score will be calculated. Any disagreement will be discussed with the senior authors until a consensus is reached.

Data extraction

One author (AL) and RAs will extract all related information into a data charting form (Table 2) in a Microsoft Excel workbook that will be pilot-tested with five included studies. When necessary, this form will be amended before starting the full review based on discussion with the senior authors during the pilot stage. The extracted data will cover (a) author and literature information (e.g. author's name, year of publication, title, type of literature, journal/source's name); (b) country of data collection; (c) focus area, study aim/purpose/objective, and research question); (d) research design (e.g. methods and study design, measures of DHL) and sampling methods; (e) key demographic information (e.g. sample size, ethnicity, and age); (f) and major findings. Studies will be classified based on their methods (qualitative, quantitative, and mixed-methods).

Table 2. Extraction table

(a) Author and literature information	(b) Country of data collection	(c) Focus area	(d) Methods	(e) Key demographic information	(f) Major findings
Qualitative studies and qualitative findings from mixed-methods studies					
<ul style="list-style-type: none"> • Author's name • Year of publication • Title • Type of literature • Journal/source's name 		<ul style="list-style-type: none"> • Study aim/purpose/objective • Research question 	<ul style="list-style-type: none"> • Research design • Study design • Measures of DHL • Sampling methods 	<ul style="list-style-type: none"> • Sample size • Ethnicity • Age 	Findings related to DHL
• ...	• ...	• ...	• ...	• ...	• ...
Quantitative studies and quantitative findings from mixed-methods studies					
<ul style="list-style-type: none"> • Author's name • Year of publication • Title • Type of literature • Journal/source's name 		<ul style="list-style-type: none"> • Study aim/purpose/objective • Research question 	<ul style="list-style-type: none"> • Research design • Study design • Measures of DHL • Sampling methods 	<ul style="list-style-type: none"> • Sample size • Ethnicity • Age 	Findings related to DHL
• ...	• ...	• ...	• ...	• ...	• ...

Data analysis and synthesis



Data in the charting form will be analysed following an inductive narrative synthesis technique used in previous reviews (Wali et al., 2018; Zhong et al., 2017). The research questions will guide the synthesis of the findings. First, a preliminary analysis will be conducted by using manual groupings to find themes and sub-themes of qualitative studies, including qualitative findings from the mixed-method study. Second, data relevant to the systematic review scope and key findings from the quantitative studies and quantitative results from the mixed-methods study will be described narratively. Lastly, the robustness of the synthesis will be assessed by locating all studies into a grid to show each contribution to the synthesis. In this stage, all steps will be primarily managed by the first author (AL) with intense discussion with the senior authors. The summary and discussion will be guided by the research questions.

Meta-analysis will be conducted by pooling at least two included randomized controlled trial (RCT) studies reporting the same outcome. The objective measure will be prioritized over the subjective measure when one primary outcome is measured with multiple measures. The meta-analysis procedure will follow the previous review protocol on the cultural adaptation of digital health interventions (Balci et al., 2020). First, the heterogeneity will be tested using the I^2 test with an assumption of the random-effects model, in which the results will be categorized into four levels of heterogeneity, including no heterogeneity (0-40%), moderate (30-60%), substantial (50-90%), and considerable (75-100%). When substantial heterogeneity is detected, subgroup analyses will be conducted to explore possible sources of this heterogeneity. Publication bias will be assessed using funnelplots or Egger's regression test (Doleman et al., 2020). Sensitivity analyses will also be conducted to explore the impact of the risk of bias on study findings. Based on the sensitivity analysis results, studies with a high risk of bias will be excluded and the meta-analysis will be repeated. Post-intervention scores of treatment and control/waiting list/alternative groups will be used to calculate the between-group effect sizes of each study. The meta-analytical effect for each outcome will be calculated with standardized mean differences and 95% of confidence intervals for continuous outcomes; and odd ratios for dichotomous outcomes. The effect sizes will be categorized into three levels, including small ($d=0.20$), medium ($d=0.50$), and large ($d=0.80$).

Ethics and dissemination

No ethical approval is needed for this systematic review because the data will be based on published studies/data. The results of this systematic review and meta-analysis will be presented at conferences and published in a peer-reviewed international journal.

DISCUSSION

The current planned study will be the first to systemically review the available DHL interventions and their effectiveness for ICs in the Asia Pacific region. The included studies with multiple languages and countries will address the knowledge gap of ICs' DHL in the Asia Pacific countries and the global efforts in improving it. This systematic review will be reported according to the Preferred Reporting Items for

Systematic reviews and Meta-Analyses (PRISMA) 2020 statement (Moher et al., 2010; Page et al., 2021). The standardized procedure and reporting will ensure the review's quality and could be used by the stakeholders in the region for planning DHL-related programs, which were dominated by studies from high-income countries and the Global North (Nguyen et al., 2021; Resciniti et al., 2020). Furthermore, this comprehensive review will also significantly contribute to dementia caregiving literature and programs for improving not only the quality of PwD care at home but also the life quality of caregivers. However, the heterogeneity in the type of ICs, form and setting of DHL interventions, and variety of outcomes might limit the interpretability.

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