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Implementation of community-based interventions for informal caregivers of people with dementia: Insights from a systematic scoping review

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Research output and products

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Protocol

BMJ Open Implementation and dissemination of home and community-based interventions for informal caregivers of people living with dementia: a systematic scoping review protocol

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Implementation Science

SYSTEMATIC REVIEW

Open Access



Implementation and dissemination of home- and community-based interventions for informal caregivers of people living with dementia: a systematic scoping review

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Abstract

Background Informal caregivers of people with dementia (PwD) living at home are often the primary source of care, and, in their role, they often experience loss of quality of life. Implementation science knowledge is needed to optimize the real-world outcomes of evidence-based interventions (EBIs) for informal caregivers. This scoping review aims to systematically synthesize the literature that reports implementation strategies employed to deliver home- and community-based EBIs for informal caregivers of PwD, implementation outcomes, and the barriers and facilitators to implementation of these EBIs.

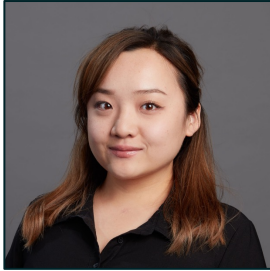
Methods Embase, MEDLINE, Web of Science, and Cochrane Library were searched from inception to March 2021; included studies focused on “implementation science,” “home- and community-based interventions,” and “informal caregivers of people with dementia.” Titles and abstracts were screened using ASReview (an innovative AI-based tool for evidence reviews), and data extraction was guided by the ERIC taxonomy, the Implementation Outcome Framework, and the Consolidated Framework for Implementation Science Research; each framework was used to examine a unique element of implementation.

Results Sixty-seven studies were included in the review. Multicomponent (26.9%) and eHealth (22.3%) interventions were most commonly reported, and 31.3% of included studies were guided by an implementation science framework. Training and education-related strategies and provision of interactive assistance were the implementation strategy clusters of the ERIC taxonomy where most implementation strategies were reported across the reviewed studies. Acceptability (82.1%), penetration (77.6%), and appropriateness (73.1%) were the most frequently reported implementation outcomes. Design quality and packaging (intervention component suitability) and cosmopolitanism (partnerships) constructs, and patient’s needs and resources and available resources (infrastructure) constructs as per the CFIR framework, reflected the most frequently reported barriers and facilitators to implementation.

Conclusion Included studies focused largely on intervention outcomes rather than implementation outcomes and lacked detailed insights on inner and outer setting determinants of implementation success or failure. Recent publications suggest implementation science in dementia research is developing but remains in nascent stages, requiring future studies to apply implementation science knowledge to obtain more contextually relevant findings and to structurally examine the mechanisms through which implementation partners can strategically leverage

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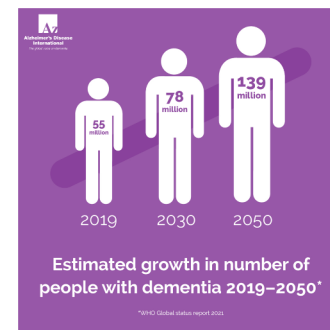
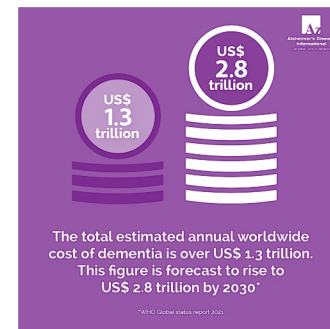
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Current progress in global dementia research

Dementia is a general term for several neurodegenerative conditions that affect cognitive function (typically in older adults), which may alter mood, memory and personality traits and limit independent living capabilities

Examples of investments in recent dementia research agendas	
Diagnostics	Conducting research on blood-based biomarkers and developing diagnostic tools to differentiate types of dementias for a more precise treatment plan
Treatment	Developing clinically effective drugs to manage dementia symptoms and slow down neurological degeneration
Prevention	Developing approaches (such as public health awareness campaigns and policies) to target modifiable risk factors early in life
Care	Developing a range of (behavioral and social) evidence-based interventions to support people with dementia and their caregivers in day-to-day activities



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Impact of informal caregivers in the healthcare system

Informal caregivers are often friends, family members and/or spouses of the person living with dementia. In Singapore, foreign domestic workers are also often in this role.

Informal care helps with:

- Reducing hospital admissions, healthcare expenditure and strain on hospital resources
- Enhancing quality of life while ageing in place (e.g., supporting home-based activities of daily living, monitoring and managing symptoms, emotional support)



89 billion
hours of informal care



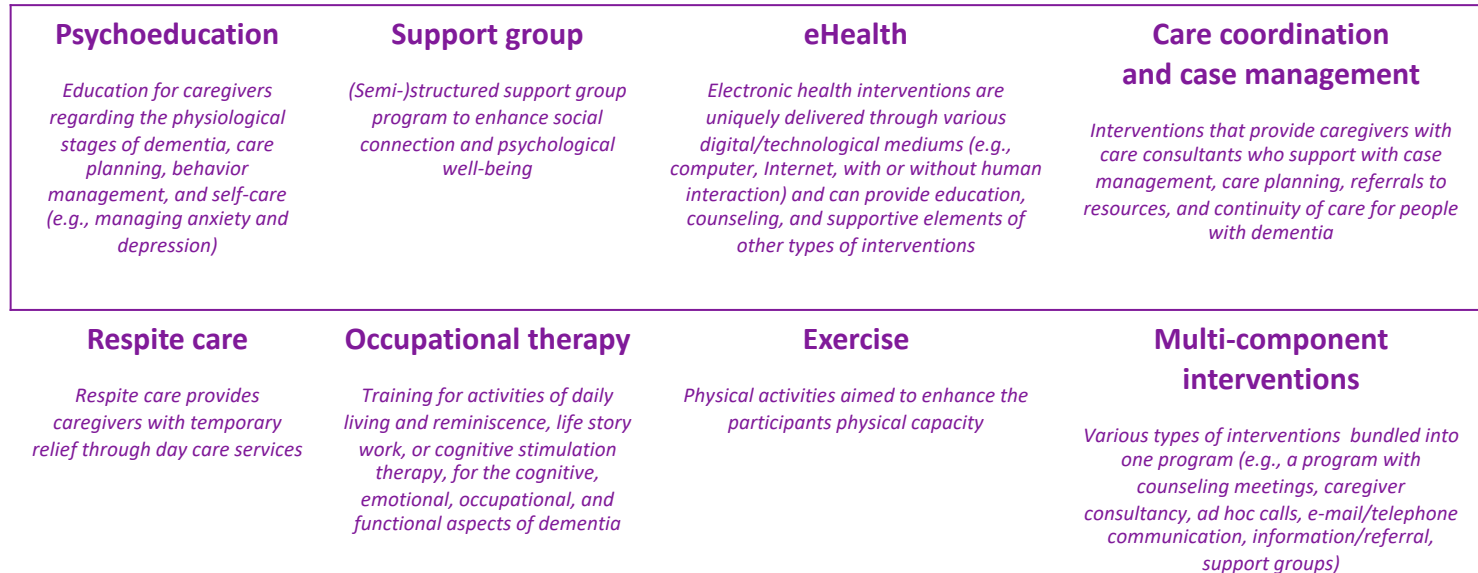
70%
of informal care is
provided by women

Support and resources for people with dementia (and informal caregivers) in Singapore



Non-pharmacological interventions for informal caregivers

A meta-review published in 2020 found 60 reviews (systematic reviews, meta-analyses) that included over 500+ interventions for informal caregivers of people with dementia, which were mainly grouped into 8 categories.



Purpose and objectives of the scoping review

Over 500 interventions exist, and many are proven to be clinically effective, but how do we get these interventions for informal caregivers of people with dementia into practice?

How have researchers conducted and reported on the implementation process?

Key objectives

Objective 1: Explore the contextual implementation barriers and facilitators that determine implementation success

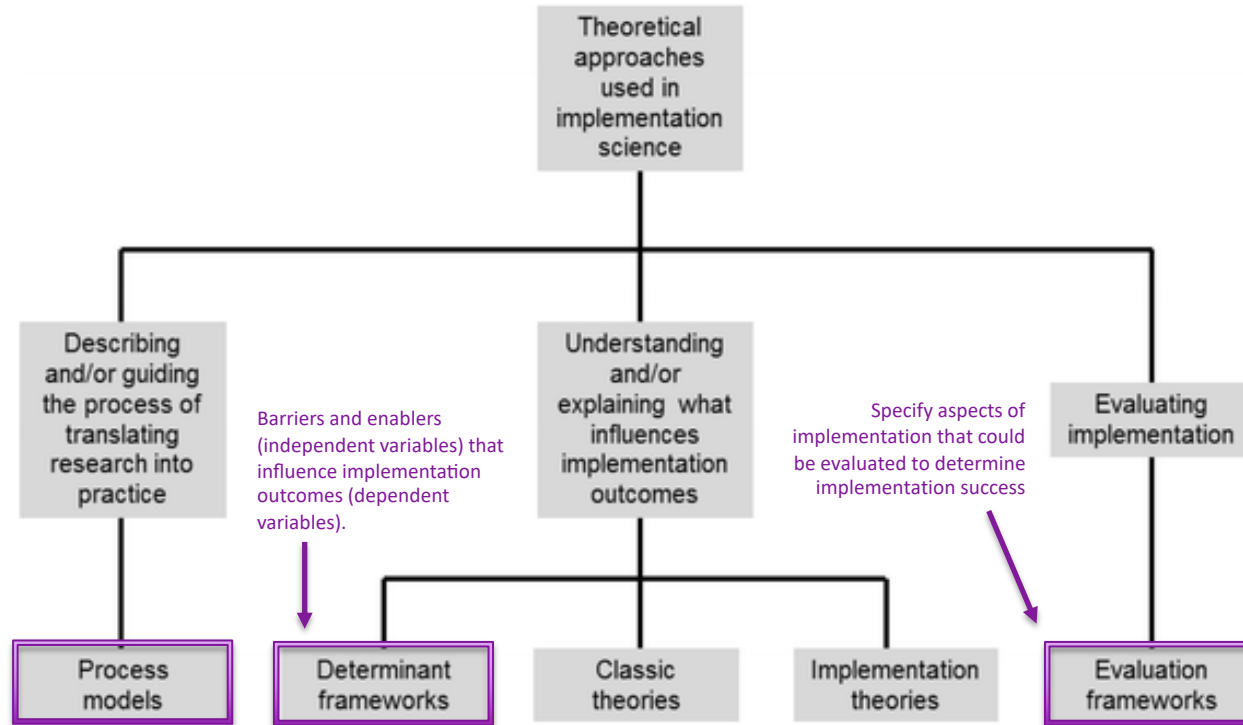
Objective 2: Explore the implementation strategies used in implementation processes

Objective 3: Explore the implementation outcomes (and indicators) reported

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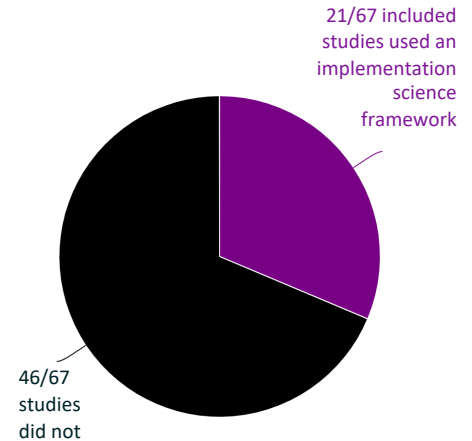
Applying implementation science theories in dementia research

How can implementation science theories be used by healthcare researchers and practitioners?



(Figure presented in Nilsen 2015)

Scoping review results



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Objective 1: Explore determinants (barriers and facilitators) to implementation

Using the Consolidated Framework for Implementation Research (CFIR)

- **Determinant framework** that provides users with a set of construct to consider when assessing the variables that influence implementation

Domains	Constructs and details
Intervention characteristics	The intervention's initial source/initiator/creator, relative advantage over existing products, strength of evidence surrounding its value, and its adaptability (or, alternatively, rigidity).
Outer setting	The wider economic, political and social context of implementation, including patient's needs and available resources, the implementing organization's position in local/regional networks, and overarching policies, regulations, and guidelines.
Inner setting	The implementing organization's structural characteristics, (formal and informal) networks and communications between employees, work culture, organizational climate, and overall readiness (organizational structure and available resources).
Characteristics of individuals	The traits of implementing team (and individuals), including personal beliefs about the intervention, self-efficacy to achieve change, individual identification within the organization (e.g., proactive mindset).
Process of implementation	Activities across the implementation process (planning, engaging, executing, and reflecting and evaluating) that are accomplished formally or informally to enact change.



Scan me to find the
updated article
(Damschroder et al. 2022)

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Objective 1: Explore determinants (barriers) to implementation of interventions

What are the contextual challenges experienced when implementing each type of intervention?

Type of intervention	Most common barriers identified	
eHealth	(Intervention characteristics) Technical issues with intervention components and poor user experience/interface design	(Outer setting) Lack of integration with existing dementia/aged care service and traditional healthcare settings (e.g., hospitals) unable to adopt intervention
Support group	(Outer setting) Financing and sustainment challenges due to ineffective reimbursement schemes (e.g., inconsistent attendance creates staffing challenges).	(Outer setting) Weak health system and resource limitations (e.g., referral pathway, network relationships,, post-diagnostic support, health financing mechanisms)
Psychoeducation	(Intervention characteristics) Unsuitable intervention delivery (e.g., long duration of session and length of program; abrupt end of intervention (post-RCT) and users losing videos/courses following the course)	(Outer setting) Lack of outreach and dissemination to community healthcare providers and paid advertisements (resulting in limited awareness of services)
Care coordination and case management	<p>(Outer setting) Fragmented local hospital system involvement with community care. Continuity of care was fragmented since caregivers were 'left to contact community support agencies independently'.</p> <p>(Inner setting) Initiators were innovation viewed as "outsiders" and "competitors" instead of collaborators.</p>	(Inner setting/Characteristics of individuals) Physicians/GP were not involved as implementation partners. Resistance for change from local hospital systems (due to physicians' time restrictions)



Objective 1: Explore determinants (facilitators) to implementation of interventions

What are the contextual factors that support the implementation of each type of intervention?

Type of intervention	Most common facilitators identified	
eHealth	(Process) Using social media marketing strategies to disseminate and strategically target reach and evaluate implementation outcome indicators via site analytics (website traffic, visitor retention)	(Characteristics of individuals) Directly engaging intervention creator and implementing agencies in the implementation process (e.g., staff training) and establish mutual familiarity and trust early
Support group	(Outer setting) Recognition and support from local community centers (church, welfare center) and local influencers across regional networks	(Outer setting) Obtaining multiple sources of financing via government-initiated incentive schemes or national legislations (e.g., municipality funding) that establish structural funding channels to claim finances from
Psychoeducation	(Outer setting) Establishing inter-agency partnerships between initiators (e.g., research team and intermediaries (e.g., nonprofit organizations) and leveraging existing resources/networks	(Outer setting) Intermediaries implement new interventions if it aligns with existing services to scale-up service provision. (Inner setting) Existing staff members are trained in this new intervention, and existing administrative infrastructure (billing/workload codes) is used to reimburse services
Care coordination and case management	(Inner setting) Implementing agency staff training was facilitated through formal education sessions (service-delivery protocol, care coordination information system explanation)	(Outer setting) Leveraging existing national policies and guidelines that encourage continuity of care and obtain local/regional government support to create and sustain intervention

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Objective 2: Explore implementation strategies used for community interventions

Using the Expert Recommendations in Implementing Change (ERIC) taxonomy

Taxonomy of 73 individual (i.e. discrete) implementation strategies, grouped into nine generalized categories, to describe the activities employed to overcome contextual barriers.

Implementation strategy categories ("clusters")	Details on specific implementation strategies
(1) Use evaluative and iterative strategies	Assess readiness and identify barriers and facilitators; audit and provide feedback; monitor and evaluate quality; conduct local needs assessment
(2) Provide interactive assistance	Facilitate; provide (and centralize) local technical assistance; provide clinical supervision
(3) Adapt and tailor to context	Tailor strategies used to address barriers previously identified and promote adaptability of intervention
(4) Develop stakeholder interrelationships	Identify change leaders; build a coalition; obtain formal commitments; visit other sites; develop an implementation glossary
(5) Train and educate stakeholders	Conduct ongoing training; provide ongoing consultation; develop educational materials; distribute educational materials
(6) Support clinicians	Remind clinicians; revise professional roles; create new clinical teams
(7) Engage consumers	Involve end-users and prepare them to be active participants; increase demand from end-users; use mass media
(8) Utilize financial strategies	Access new funding; place innovation on fee for services list/formularies; make billing easier
(9) Change infrastructure	Change record systems and physical structures/equipment; change credentialing/licensure standards; start a dissemination organization



Scan me for the full
ERIC taxonomy



Objective 2: Explore implementation strategies used for community interventions

What are the most common implementation strategies used in the implementation process for each type of intervention?

Type of intervention	Example of Implementation setting and implementing actors	Most common implementation strategies used	
eHealth	<p>iSupport (WHO)</p> <ul style="list-style-type: none"> Dissemination facilitated by WHO team and partnering organizations <p>InLife (NL)</p> <ul style="list-style-type: none"> Community-based organizations; DAZ (external agency) conducted training 	<p>Cluster 3 (Adapt and tailor to context)</p> <ul style="list-style-type: none"> ERIC 63 (Tailor [implementation] strategies) <p><i>E.g., Website was provided alongside a toll-free telephone service to enhance access to intervention</i></p>	<p>Cluster 5 (Train and educate stakeholders)</p> <ul style="list-style-type: none"> ERIC 31 (Distribute educational materials) ERIC 29 (Develop educational materials) <p><i>E.g., Spanish-language content for caregivers was developed by translators to promote wider usability</i></p>
Support group	<p>Meeting Centre Support Program (NL/UK/IT/PL)</p> <p>Community centres (and centres for the elderly) by a small and permanent team of professionals (a programme coordinator)</p>	<p>Cluster 4 (Develop stakeholder interrelationships)</p> <ul style="list-style-type: none"> ERIC 6 (Build a coalition); ERIC 35 (Identify and prepare champions); ERIC 47 (Obtain formal commitments); ERIC 52 (Promote network weaving) <p><i>E.g., Community engagement and collaboration (across sector) with existing local care and welfare organizations to reduce health system fragmentation and resource limitations</i></p>	

Objective 2: Explore implementation strategies used for community interventions

What are the most common implementation strategies used in the implementation process for each type of intervention?





Type of intervention	Implementation setting and implementing actors	Most common implementation strategies used	
Psycho-education	<p>Tele-Savvy for Dementia Caregivers The Savvy Caregiver Program (USA)</p> <ul style="list-style-type: none"> Department of Veterans Affairs–supported clinical T-21 Non-Institutional Alternatives to Long Term Care clinical demonstration project. Staff in research service (not clinical staff, thus affecting the real-world sustainment) 	<p>Cluster 5 (Train and educate stakeholders)</p> <ul style="list-style-type: none"> ERIC 19 (Conduct ongoing training); ERIC 29 (Develop educational materials); ERIC 31 (Distribute educational materials); Cluster 5/ERIC 43 (Making training dynamic) <p><i>E.g., Medway Carers Course was developed by specialist psychologists responding to clinical need for care focused on PwD and relatives.</i></p> <p><i>E.g., Training was facilitated through treatment manual, role-playing, structured practice with behavioral problem-solving plans using videos.</i></p>	
Care coordination and case management	<p>Cleveland Alzheimer's managed Care Demonstration (USA)</p> <ul style="list-style-type: none"> Care consultation is delivered by one of three Alzheimer's Association staff members, two of whom are master's prepared licensed social workers 	<p>Cluster 4 (Develop stakeholder interrelationships)</p> <ul style="list-style-type: none"> ERIC 52 (Promote network weaving); ERIC 24 (Develop academic partnerships) <p><i>E.g., Establishing formal partnership between Veteran Affairs (USA) medical center and Alzheimer's association chapters</i></p>	<p>Cluster 6 (Support clinicians)</p> <ul style="list-style-type: none"> ERIC 59 (Revise professional roles); ERIC 30 (Develop resource-sharing agreements) <p><i>E.g., Care consultation delivered by Alzheimer's Association staff members who are master's prepared social workers</i></p>

Objective 3: Explore implementation outcomes and how they were reported

Implementation Outcome	How outcomes were reported by included studies
Acceptability	The intervention's "suitability," "usability," and "helpfulness" for users.
Appropriateness	End users' and implementing agencies' "satisfaction" with intervention effectiveness and components; the perceived 'fit' of the intervention into the implementation agency
Penetration	Can be used to evaluate organization or setting; studies mainly applied this to the setting and descriptively reported how users were recruited, including marketing strategies, and leveraging financial resources and interpersonal relationships from cross-sector partners.
Sustainability	Described as users' and organizations' "demand for program continuation" and "routinization of care." Studies mainly focused on describing the existing internal and external financing mechanisms and the role of collaborators and external agencies in training and scaling up.
Implementation fidelity	Described as the facilitators' degree of "adherence" to the implementation protocol. Implementation fidelity enhancing strategies included protocolizing implementation, training certification programs with initiators, and using fidelity checklists and guiding scripts.
Adoption	Described as how administrations are motivated to "buy into" the intervention and how the engagement of local "influencers" promotes user uptake.
Feasibility	Described as the degree to which intervention components fit within the organization and how components are pragmatically streamlined into existing workflow
Implementation cost	Reported as how operational and staffing costs were covered, mainly through government- regulated financing programs (e.g., Medicare, Social Support Act, Older Americans Act)



Overview of study objectives and methodological approaches used

Research objectives	Theoretical framework used <i>(Please scan QR codes for the original articles)</i>	
Explore the contextual implementation barriers and facilitators that determine implementation success	Consolidated Framework for Implementation Research (CFIR)* <i>*We recommend using the updated version published in 2023</i>	
Explore the implementation strategies used in implementation processes	Expert Recommendations for Implementing Change (ERIC) taxonomy	
	Waltz's Implementation Strategy Clusters	
Explore the implementation outcomes (and indicators) reported	Implementation Outcomes Framework	

Main takeaways and future direction

Potential future opportunities

Perform scoping/systematic reviews using multiple lenses, as performed in this study, to understand implementation comprehensively.

- To understand *how* researchers are conducting implementation research in various settings and which stakeholders are involved and when they are involved.
- To work across systems and foster implementation collaborations that support scale-up and sustainability
- To explore contextual barriers (and impact of strategies) in various implementation settings (such as LMICs, areas with underrepresented population groups)

Expanding knowledge on the use of implementation science in community environments (outside of hospitals) by elaborating on community-level strategies (which may be different from clinical implementation strategies)

Objective 1: Explore determinants (barriers and facilitators) to implementation



Future studies should elaborate on whether studies conducted an initial contextual assessment prior to selecting implementation strategies.

Objective 2: Explore implementation strategies used for community interventions



Future studies should conduct evaluative studies to understand why strategies work (or fail) under which conditions.

Objective 3: Explore implementation outcomes reported for dementia literature



Contact information

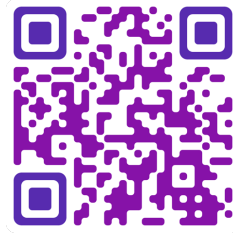
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