Full Title: Supports for Informal Caregivers of People Living with Dementia in The Middle East and North Africa Region: Realist Review
Short Title: Dementia and Informal Caregivers supports in the MENA Region
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Abstract
In the Middle East and North Africa (MENA) region, the commitment to honour parents and keeping private "issues" within the home all combine to shape caregiving styles and needs. Given the lack of evidence on the effectiveness of interventions for informal caregivers for people living with dementia in the MENA region, this study offers an overview of interventions for caregivers. It will also explore informal caregivers' needs, preferences, and views about addressing intervention through online content. This study includes the development of a middle-range programme theory to provide insight into the mechanisms underpinning the interventions.

A realist review approach was used to explore what intervention types and features support the informal caregivers of people living with dementia throughout the MENA region. It also examined under which contexts and how these interventions worked. The realist synthesis involved 23 papers from MEDLINE Complete, CINAHL, A PsycInfo, Web of Science, Scopus databases, and eight interviews with health professionals. Context–mechanism–outcome configurations (CMOCs) were extrapolated to build and iteratively refine the middle-range programme theory and finalise it for testing.Eight CMOCs were extrapolated from the data to form the middle- range programme theory. Contextual conditions that emerged included stigma, long care duration, culture, lack of support, and the effect of this on intervention uptake. Mechanisms reported include feeling supported and empowering caregivers with skills, knowledge and support they needed, which led to outcomes including improving the quality of life for people living with dementia and caregivers and reducing stress.

This study identified preliminary support for the contexts, mechanisms and outcomes underpinning the interventions in the MENA region. This paper will contribute to the limited literature by addressing an identified gap in knowledge by supporting the understanding of informal caregivers of people living with dementia in the MENA region to understand why particular interventions work or not and in what contexts.

Introduction

Care provision for dementia, and social and cultural views about caring, differ by region and culture. Most studies on dementia caregiving have been in the West, where ageing communities and long-term care homes are established and reliable living arrangements. In Arab societies, there is perhaps a stronger expectation that families will manage, and that mental health problems will be kept private. These expectations have helped to shape the caregiving landscape and the experiences of informal caregivers (see, for example, Abdelmoneium & Alharahsheh, 2016). Throughout the Middle East and North Africa (MENA), religious and cultural views suggest family members are the obvious caregivers (see, for example, Abyad, 2015). However, family caregivers struggle with the emotional, physical, financial, and psychological impact of supporting someone living with dementia (Al Sulaiti et al., 2008).

Several recent studies and reviews have explored the experiences of informal dementia caregivers in the MENA region (Abdelmoneium & Alharahsheh, 2016; Alshammari et al., 2017; Barbarino et al., 2020; Kane et al., 2021; Yaghmour et al., 2019). They have provided overviews of the experiences, characteristics, needs, and challenges of this group. Caregivers particularly wanted training (Abyad, 2015), access to knowledge, and support (Kane et al., 2021). Some researchers have suggested how to improve dementia care or support caregivers (Abdelmoneium & Alharahsheh, 2016; Barbarino et al., 2020; Kane et al., 2021).

Caregivers need skills and support to provide effective care and avoid being overwhelmed. Interventions may reduce the psychological distress of informal caregivers (Beinart et al., 2012). Studies in Egypt and Iran have examined the outcomes of interventions for informal caregivers. In Egypt, Shata et al. (2017) investigated multi-component psychosocial intervention, psychoeducational programmes, and educational training. They and others (Abdelzaher et al., 2022; Tawfik et al., 2021) showed that these interventions improved quality of life and reduced the impact of informal caregiving for people living with dementia. Studies from Iran cover multiple interventions, including compassion-based programmes, educative support groups, and spiritual group therapy using different content, structures and mechanisms (Ghezlesefloo et al., 2019; Jahani et al., 2022; Javadpour et al., 2009; Mahdavi et al., 2017;

Noroozian & Mohammadian, 2021; Saadati et al., 2014). All these interventions positively affected caregivers' mental health.

Work from the Doha International Family Institute (2020) found a high demand for support and information for caregivers, which is expected to increase. The population in the region continues to age; by 2050, the proportion of older people is projected to be between 12% and 19% in most countries (United Nations Department of Economic and Social Affairs, 2019). The number of people living with dementia is also expected to increase (World Health Organization, 2012).

This research project therefore explores dementia care in the MENA region, hoping to identify new perspectives to support more inclusive, client–family-centred approaches to care support, implementation, and delivery. The review question is "*What types and aspects of interventions support informal caregivers of people with dementia in the MENA region, in which contexts, and how?* "

To the author's knowledge, this is the first review of its kind to investigate interventions for dementia caregivers in this region. The study used interviews with healthcare professionals to explore reasons and solutions for the attrition rates of interventions. It also explored interviewees' views and experiences of online interventions. It is hoped that it will improve outcomes for caregivers and recipients by enabling development of culturally-appropriate and need-based interventions for people with dementia and their caregivers.

Method

There are few relevant studies in the region, especially high-quality, evidence-based studies on interventions. A traditional systematic review was therefore unsuitable because of the risk of over-specificity (Pawson et al., 2004, 2005). Instead, this study used a realist review. Here, the theory is the unit of analysis (Pawson et al., 2005), allowing the inclusion of studies reporting findings on different interventions but linked by theory. It was considered that this approach would provide flexibility in investigating a complex subject.

The review followed the six steps set out by Pawson (2006a). These are identifying the review question, searching for studies, quality appraisal, extracting the data, synthesising the data and disseminating the findings. The review combined interviews with healthcare professionals and literature searches. It was carried out in iterative stages, including identifying the scope of the review, conducting extensive lateral searches, screening, data extraction and analysing and synthesising findings. The review consisted of two phases guided by the Realist and Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) criteria for realist reviews (Wong et al., 2013).

1. Identifying the review question

This step included a non-systematic scoping of the literature and interviews with stakeholders, which is important in realist reviews (Pawson, 2006a; Rycroft-Malone et al., 2012). Stakeholders "have some content expertise about the topic area" (Wong, 2018, p.134) and help to make sense of the subject (Wong et al., 2013). The stakeholders here were healthcare professionals from different backgrounds and countries in the region. The interviews were designed to identify gaps in interventions, and papers, resources and documents that might be useful, and increase understanding of the review subject. This process supported the development of candidate theories. Ethical approval for the interviews was given by the Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHM-2022-0990-RECR-2)..

Potential participants had direct involvement in providing interventions to informal caregivers of people living with dementia. They were identified by searching the websites of health organisations, and dementia and Alzheimer's associations for each country in the region. At least one person from each country was invited to participate in a semi-structured interview via telephone or online using Microsoft Teams. The inclusion criteria were:
- Paid health professionals with experience in designing, implementing and using interventions and support for informal caregivers of people living with dementia.
- English or Arabic speaker; and

- Employed in one of the 19 countries in the MENA region (World Bank, 2022).

Interviews were digitally recorded and transcribed verbatim. A topic guide was developed that would accommodate in-depth questioning about particular issues (Manzano, 2016). The interviews discussed emerging ideas from the literature and whether these corresponded to the interviewees' experience. The interviewees were asked to provide an overview of interventions in their countries, explore how different interventions might increase positive outcomes, explain the relationship between context and mechanism and describe the outcomes for caregivers who used the intervention. They were also asked their opinions on online interventions.

The review question that emerged was:

What types and aspects of interventions support informal caregivers of people with dementia in the MENA region, in which contexts, and how?
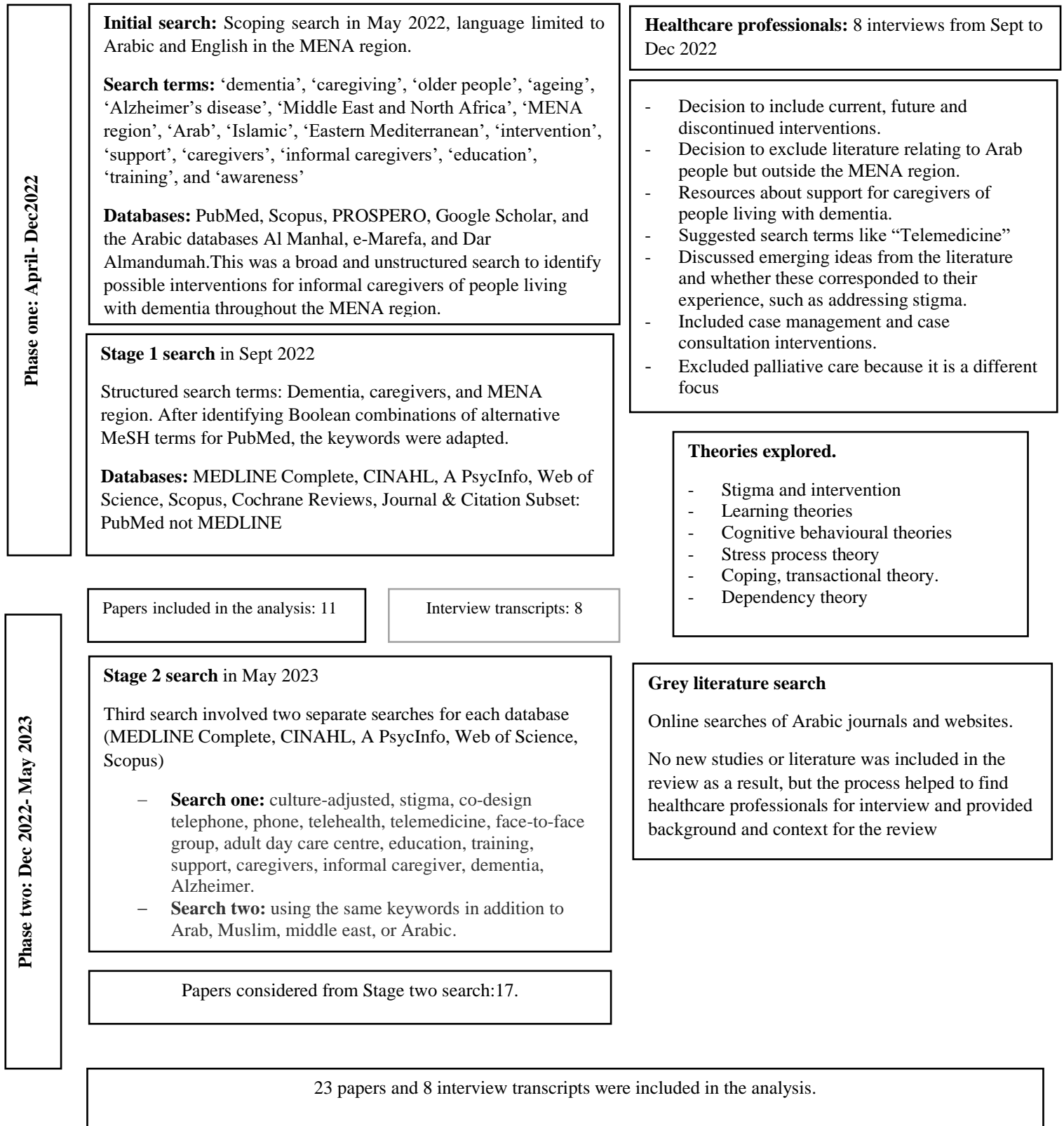
The review aimed to:

- Provide an overview of interventions in the region for informal caregivers of people living with dementia;
- Identify which interventions are helpful in which contexts, and the mechanisms behind them;
- Understand why attrition occurs from interventions and how to reduce it;
- Identify suitable practices, resources, and processes to support interventions; and
- Understand what matters when developing online interventions.

2. Literature search

A two-stage literature search was conducted (Figure 1). The initial search in May 2022 aimed to identify research gaps and opportunities. It scoped out the information, training, skills building and support resources available to people with dementia and their informal caregivers throughout the region. It also looked at the value of these interventions, including their overall helpfulness, ease of use, and accessibility, and generated hypotheses and search terms for the second stage.

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Figure 1. The review process: A two-stage search strategy

Phase one: April- Dec 2022

Initial search: Scoping search in May 2022, language limited to Arabic and English in the MENA region.

Search terms: 'dementia', 'caregiving', 'older people', 'ageing', 'Alzheimer's disease', 'Middle East and North Africa', 'MENA region', 'Arab', 'Islamic', 'Eastern Mediterranean', 'intervention', 'support', 'caregivers', 'informal caregivers', 'education', 'training', and 'awareness'

Databases: PubMed, Scopus, PROSPERO, Google Scholar, and the Arabic databases Al Manhal, e-Marefa, and Dar Almandumah.This was a broad and unstructured search to identify possible interventions for informal caregivers of people living with dementia throughout the MENA region.

Stage 1 search in Sept 2022

Structured search terms: Dementia, caregivers, and MENA region. After identifying Boolean combinations of alternative MeSH terms for PubMed, the keywords were adapted.

Databases: MEDLINE Complete, CINAHL, A PsycInfo, Web of Science, Scopus, Cochrane Reviews, Journal & Citation Subset: PubMed not MEDLINE

Healthcare professionals: 8 interviews from Sept to Dec 2022

- Decision to include current, future and discontinued interventions.
- Decision to exclude literature relating to Arab people but outside the MENA region.
- Resources about support for caregivers of people living with dementia.
- Suggested search terms like "Telemedicine"
- Discussed emerging ideas from the literature and whether these corresponded to their experience, such as addressing stigma.
- Included case management and case consultation interventions.
- Excluded palliative care because it is a different focus

Theories explored.

- Stigma and intervention
- Learning theories
- Cognitive behavioural theories
- Stress process theory
- Coping, transactional theory.
- Dependency theory

Papers included in the analysis: 11

Interview transcripts: 8

Phase two: Dec 2022- May 2023

Stage 2 search in May 2023

Third search involved two separate searches for each database (MEDLINE Complete, CINAHL, A PsycInfo, Web of Science, Scopus)

- **Search one:** culture-adjusted, stigma, co-design telephone, phone, telehealth, telemedicine, face-to-face group, adult day care centre, education, training, support, caregivers, informal caregiver, dementia, Alzheimer.
- **Search two:** using the same keywords in addition to Arab, Muslim, middle east, or Arabic.

Papers considered from Stage two search:17.

Grey literature search

Online searches of Arabic journals and websites.

No new studies or literature was included in the review as a result, but the process helped to find healthcare professionals for interview and provided background and context for the review

23 papers and 8 interview transcripts were included in the analysis.

Stage 1 search

Keyword searches were performed of PubMed, Scopus, PROSPERO, Google Scholar, and the Arabic databases Al Manhal, e-Marefa, and Dar Almandumah. The keywords were: 'dementia', 'caregiving', 'older people', 'ageing', 'Alzheimer's disease', 'Middle East and North Africa', 'MENA region', 'Arab', 'Islamic', 'Eastern Mediterranean', 'intervention', 'support', 'caregivers', 'informal caregivers', 'education', 'training', and 'awareness'.

The second search, in September 2022, was guided by the preliminary findings and used additional databases and search engines. Boolean combinations of MeSH terms were identified for PubMed, and adapted and used for MEDLINE Complete, CINAHL Complete, PsycINFO, Web of Science, Scopus, Cochrane Library, and Journal and Citation Subset: PubMed. The findings iteratively informed the inclusion and exclusion criteria. Extensive lateral search techniques were also used, including:

- Examining the reference lists of papers;
- Snowballing, i.e., tracking citations forward and backward
- Performing keyword searches in Google Scholar;
- Searching grey literature;
- Exploring the websites of hospitals, non-profit organisations, and patient and caregiver associations;
- Asking interviewees for additional resources;
- Viewing documents about interventions and the national dementia strategies in the region.

The search continued throughout the synthesis process, with assumptions and theoretical foundations being refined until saturation was achieved (Pawson et al, 2005; Wong et al., 2010).

Stage 2 search

A third search was carried out based on the links between 'If… then...' statements and the identified interventions in Figure 2. This included two separate searches for each

database (MEDLINE Complete, CINAHL, PsycInfo, Web of Science, Scopus) in May 2023. Search one used the terms 'culture-adjusted', 'stigma', 'co-design', 'telephone', 'phone', 'telehealth', 'telemedicine', 'face-to-face group', 'adult day care centre', 'education', 'training', 'support', 'caregivers', 'informal caregiver', 'dementia', and 'Alzheimer'. These were adapted or adjusted to fit the search criteria for each database. Search two added 'Arab', 'Muslim', 'Middle East', or 'Arabic'.

This search explored alternative interventions and was not limited to the MENA region to avoid missing any ideas or concepts used internationally but not in this region. Searching was iterative because new or refined elements of the theory were needed to examine or explain specific findings during the synthesis. The search continued until enough evidence was obtained to develop theories (Pawson et al., 2005).

Screening

Stage 1 search

The search results were downloaded into bibliographic software (EndNote), and duplicate entries were manually removed. Titles and abstracts were screened for relevance. Potentially relevant studies were read in full to assess their relevance and rigour (trustworthiness) (Pawson, 2006b; Wong, 2018). Ten percent of the papers were also reviewed by the researcher's Ph.D. supervisors Caroline Swarbrick (CS) and Carol Holland (CH).

The inclusion criteria for studies were:

- Focused on informal caregivers of people living with dementia;
- Described interventions available to informal caregivers (possibly among others), where data about informal carers could be separated;
- Included interventions for people living with dementia and their informal caregivers.
- Assessed daily activities and needs of informal caregivers of people living with dementia in a home setting in the MENA region.
- Described primary empirical research of any design.
- Written in English or Arabic.

Studies were excluded if: the intervention focused on (1) only people living with dementia with no data about caregivers; or (2) caregivers of people living with dementia, but in a hospital or assisted living setting; and (3) the study was outside the MENA region.

Stage 2 search

The same process was used to identify papers that:

- Covered interventions available to informal caregivers.
- Described interventions for people living with dementia and their informal caregivers.
- Included at least one of the following terms: culture-adjusted, stigma, co-design, telephone, phone, telehealth, telemedicine, face-to-face group, adult day care centre, education, training, support, caregivers, informal caregiver, dementia, Alzheimer, Arab, Muslim, Middle East, or Arabic.

Full texts were screened for relevance and rigour in discussion with CS and CH (Pawson, 2006a; Wong et al., 2013).

3. Quality appraisal

Papers that are poorly designed and executed can still contain 'nuggets' of valuable information for a realist review (Pawson, 2006b; Wong, 2018). Studies were therefore only excluded if they did not contribute to addressing the review question (Pawson et al., 2005; Wong, 2010). A random sample of 10% of the articles was selected, screened, and discussed with CS and CH. This was to: (1) ensure that inclusion was based on relevance and rigour; (2) safeguard the integrity and fidelity of the decision-making process; and (3) resolve any differences of opinion. Consideration of the contribution and reliability of the evidence continued throughout the data synthesis as concepts developed and appraisals of the data were shared and debated with CS and CH. The characteristics that indicated 'relevance' and 'rigour' in each text were documented in each text were documented in an Excel spreadsheet (Pawson, 2006b; Wong, 2018).

4. Extracting the data

This part of the work aimed to filter and code relevant sections of text that may be useful to developing the middle range programme theory. This was especially for information related to context–mechanisms–outcome configurations (CMOCs). Framework analysis was used to analyse interview transcripts from health professionals, as well as the selected papers from the literature identified in Stage 1 of the realist review (Ritchie & Spencer, 2002). Three framework matrices were created in Excel as Sheet 1. Interventions, Sheet 2. Reasons behind attrition rates, and Sheet 3. Online intervention options.

This process of data extraction was iterative during the period from September 2022 to February 2023. Data were entered into an Excel spreadsheet and then a Microsoft Word document. A list of 11 'If... then …' statements were developed, and seven 'If... then...' statements were selected they were considered to specify how and what thought to influence and support the leading outcomes in the different interventions (See Supplementary Material, 1). These served as the foundation for the development of CMOCs. The outputs were discussed with CS and CH during this stage.

5. Synthesising the data

Realist reviews adopt a theory-driven approach to synthesis (Wong et al., 2013). Here, the synthesis took the form of context–mechanisms–outcome configurations (CMOCs). These underpinned the middle range programme theory. The study used best practices in adjudication and triangulation to refine the theories that cut across studies and to interpret findings. Evidence about context, mechanism, and outcomes was extracted to a table, and synthesised and presented as diagrams. The data were organised into categories by type of intervention and discussed with CS and CH .

6. Dissemination of the findings

To help refine theories and ensure findings are applicable and valuable in real-world contexts, the work was submitted to two conferences and feedback from delegates with a wider range of expertise elicited. It was presented at the British Society of Gerontology 52nd

Annual Conference 2023, held at the University of East Anglia (UEA) from 5–7 July 2023.Also in the 3ʳᵈ Qatar International Geriatrics and Dementia Conference, hosted by HMC's Department of Geriatrics & Long-term care under the aegis of the WHO Collaborating Centre for Healthy Aging and Dementia from 26-28 October 2023 provided an opportunity to engage directly with healthcare professionals who worked with people living with dementia and caregivers.

Framework analysis

Framework analysis has been used in healthcare research (Ward et al., 2013), dementia care research (Sampson et al., 2008; Smebye et al., 2012), and to develop theories in realist reviews and evaluations (Abhyankar et al., 2013; Bhanbhro et al., 2016). It was therefore considered suitable to create initial theories by bringing together information from different sources (Gale et al., 2013). Framework analysis in this study involved a five-step process: familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretation.

1.Familiarisation

Familiarisation was achieved by reading the interview transcripts and papers repeatedly and making notes about the themes, similarities and variations and their relationship with the review question. Regular discussions with CS and CH about the emerging concepts and themes assured consistency.

2. Identifying a thematic framework

After familiarisation, an initial coding framework was developed using the aims of the review. This framework provided guidance to shape data collection and analysis, but sufficient flexibility to allow new ideas to emerge. This stage focused on the themes behind the study aims, raised by the healthcare professionals, or emerging from patterns in the data. The coding framework was adapted and refined to add emerging themes, seeking new mechanisms and context explanations where needed. The analysis focused on developing explanations of the programme theories behind the interventions identified as the most useful for informal caregivers in the region. This created a new structure for the data to help

develop the CMOCs and eventually answer the review question (See Supplementary Material, 2).

3. Indexing (coding)

Manual coding was used to identify the contexts and mechanisms for each intervention and the associated outcomes in studies and interview transcripts. Different themes were highlighted using different colours. Candidate theories were framed as patterns or demi-regularities started to emerge. Coding was both inductive (in response to emerging data) and deductive (informed by the study objectives). The coding context was from one or two sentences to a paragraph. Where text was relevant to several themes, data were multiply coded. Codes were discussed and debated with CS and CH (See Supplementary Material, 2).

4. Charting

Three framework matrices were created on interventions, reasons for attrition rates, and online interventions. All interviews and papers were included in each matrix, but not all cells contained data. Charting involved abstraction and synthesis of data on themes, for each cell.

5. Mapping and interpretation

Data were mapped and interpreted to define the concepts and identify candidate theories. A narrative account of the evidence was created for each data source. Diagrams were created for useful interventions (3), to help explain the associations. These were also set out using seven "If... then..." statements. A conceptual framework (Pawson, 2006a) was developed based on discussion of the seven "If... then..." statements. This grouped the statements into two areas (Figure 2) and informed Stage 2 of the literature search and synthesis. The results were used to develop the CMOCs.

Results

In Phase 1, eight interviews with healthcare professionals and 11 papers supported the development of seven 'If ... then...' statements that defined the focus of the review. A structured, iterative review process identified that the majority of evidence reported outcomes for interventions, with limited information about why those interventions worked or if they were ongoing. Phase 2 included evidence from 23 papers and contributed to the development of eight CMOCs. The results of the review process are shown in Figure 1 and see Supplementary Material, 4.

Interviews

Interviews were carried out with eight healthcare professionals from different backgrounds: two psychiatrists, two geriatrics physicians, one general physician, two social workers, and one psychiatric nurse who worked in hospitals, associations or universities, with work experience in dementia fields between five to more than 11 years each lasting between 25 minutes and one hour (See Supplementary Material, 5). The interviewees discussed their experiences of designing and implementing interventions for informal caregivers of people living with dementia. They also provided their views on how the interventions worked. They discussed outcomes and the range of interventions used, as well as other possible interventions. The interviews gave insights into how interventions were believed to work and added to the evidence from the literature (Manzano, 2016). The process helped to identify gaps, improve understanding of how context affected outcomes, and initiate thinking about potential mechanisms. It also supported the development of candidate theories.

A narrative account of the evidence was created to understand the factors affecting interventions. The interventions were summarised into psychoeducational; multi-component, supportive; respite; psychotherapy; exercise; and miscellaneous interventions (Sörensen et al., 2002). Two additional categories were added (Pendergrass et al., 2015): informational interventions and case and care management. Interviewees discussed future, current, and discontinued interventions. They also expressed opinions about which

interventions were effective and in which contexts. For example, the below is an opinion about the telephone helpline:

".. It sort of helps in minimizing the stigma because the first contact is through a phone call, and when they realize culture through the phone call that it is a compassionate, confidential service. They're able to make the next step." (S01).
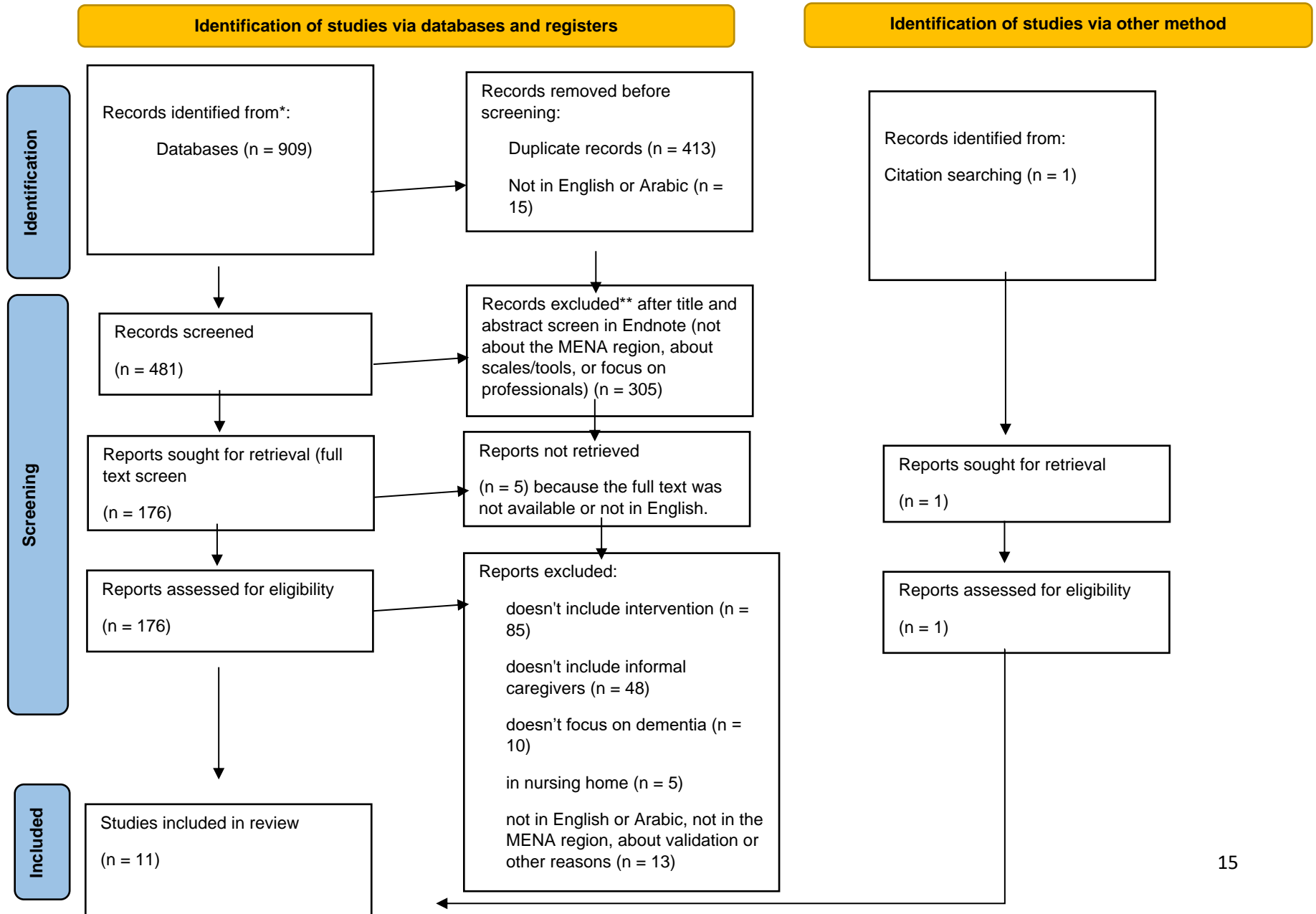
The healthcare professionals attributed the delayed help-seeking and late-stage dementia diagnoses to a lack of awareness, stigma, and privacy concerns. To address this, professionals discussed interventions like seminars, lectures, and talks to raise awareness through face-to-face, radio, and online interactions.

"The patient comes at a late stage, it's hard to help with the current treatments which currently working on the early stages, but it was our goal to urge people to recognize illness at the beginning and acceptance of help in the first stages on the basis that we start treatments and use strategies that can reduce the challenges of difficult behaviours"(S08).

Papers included in Stage 1 of the review

A PRISMA flow diagram was used to show the studies identified and excluded at Stage 1 of the review process. The full text of 177 articles was sought; five were not found. The reasons for exclusion were documented in Excel sheet. Overall, 167 studies were excluded because (1) there was no intervention, (2) the intervention was not for informal caregivers of people living with dementia, (3) the target group was people living in nursing homes, (4) the study was outside the MENA region, (5) the study was about screening tools, and (6), the study was clinical and about genes. In total, 11 papers, all from Iran or Egypt, discussed interventions to support informal caregivers for people living with dementia in the MENA region (Figure 2 and Table 1 in Supplementary Material, 4).

Figure 2. PRISMA flow diagram for papers included in Phase 1.

Identification of studies via databases and registers

Identification of studies via other method

Identification

Records identified from*:

Databases (n = 909)

Records removed before screening:

Duplicate records (n = 413)

Not in English or Arabic (n = 15)

Records identified from:

Citation searching (n = 1)

Screening

Records screened

(n = 481)

Records excluded** after title and abstract screen in Endnote (not about the MENA region, about scales/tools, or focus on professionals) (n = 305)

Reports sought for retrieval (full text screen

(n = 176)

Reports not retrieved

(n = 5) because the full text was not available or not in English.

Reports sought for retrieval

(n = 1)

Reports assessed for eligibility

(n = 176)

Reports excluded:

doesn't include intervention (n = 85)

doesn't include informal caregivers (n = 48)

doesn't focus on dementia (n = 10)

in nursing home (n = 5)

not in English or Arabic, not in the MENA region, about validation or other reasons (n = 13)

Reports assessed for eligibility

(n = 1)

Included

Studies included in review

(n = 11)

15

Psychoeducational interventions

Most of the papers mentioning psychoeducational interventions were from Iran, with one from Egypt. The interventions included:

- A compassion-based programme to reduce grief (Jahani et al., 2022);
- Face-to-face group sessions to increase resilience among caregivers of people with Alzheimer's (Ghaffari et al., 2019; Ghezelsefloo et al., 2019);
- Training for caregivers about dementia behaviours and problems, and an interactive self-support group (Javadpour et al., 2009); and
- An educational programme to increase knowledge about dementia and provide peer support for caregivers (Abdelzaher et al., 2022).

Helplines

Helplines were mentioned in two studies from Iran. The first was a compassion-based programme on grief (Jahani et al., 2022). The helpline was provided by a nurse, and caregivers were given the number in sessions run by the nurse, under the supervision of a psychiatrist. Caregivers could ask questions, comment or discuss their experiences using the helpline. The other study was an evaluation of one year of using telemedicine with people living with dementia. It mentioned a helpline used by many caregivers during the pandemic, but no more information was provided (Noroozian & Mohammadian, 2021).

Multi-component psychosocial intervention programme

One study described a programme in Egypt for informal caregivers of people living with dementia. It included eight face-to-face weekly group training sessions based on caregivers' needs identified in an early assessment interview. More than half mentioned that they needed psychological support. The programme included psychoeducation (two sessions), brief group cognitive behavioural therapy (six sessions), and group support sessions. The short-term outcomes were positive, including reduced depression, anxiety, and concerns about caring, and increased dementia-related knowledge. However, only this increase in knowledge remained three months later (Shata et al., 2017).

Psychotherapy

One study from Iran targeted female caregivers for people with Alzheimer's disease who can speak and listen to Persian. It included 12 weekly face-to-face gestalt group therapy sessions to help them live in the present and increase their positive emotions. Different methods, such as planning dreams and empathy seats, increased their awareness of themselves and helped them complete uncompleted tasks (Saadati et al., 2014).

Spiritual interventions

Other interventions included spiritual group therapy and spiritual care education for Muslim main caregivers (Mahdavi et al., 2017; Salamizadeh et al., 2017). Both studies included five sessions adjusted to Iranian culture and Islam, for caregivers of people with Alzheimer's disease who can read and write in Persian with minimum on year care experience. The sessions included an introduction and information on group solidarity, the role of reciting the Quran and the recommended performances and repeating them in personal peace, and an explanation of the experience of spiritual care and its effects. They helped release negative emotions, increase coping abilities, reduce care stress, and increase self-efficacy.

Telemedicine

In 2021, when COVID-19-related restrictions were in force in Iran, many families sought help with dementia via the Yaadmaan helpline. A telemedicine programme using WhatsApp was therefore started for people living with dementia and their informal caregivers. A multidisciplinary team provided advice about managing telemedicine consultations, and pharmacological, non-pharmacological, neuropsychological and neuropsychiatric assessment interventions, and education by the dementia nurse. This helped to reduce stress on caregivers (Noroozian & Mohammadian, 2021).

If… then... statements

Based on the emerging evidence, 11 'if... then...' statements (Pearson et al., 2015) were generated and refined through discussion. The aim was to understand how

interventions work, for whom, under what circumstances and how. The 11 statements were refined to seven and the connections between those seven statements are summarised in Figure 3.

Figure 3. The connections between the 'If… then...' statements
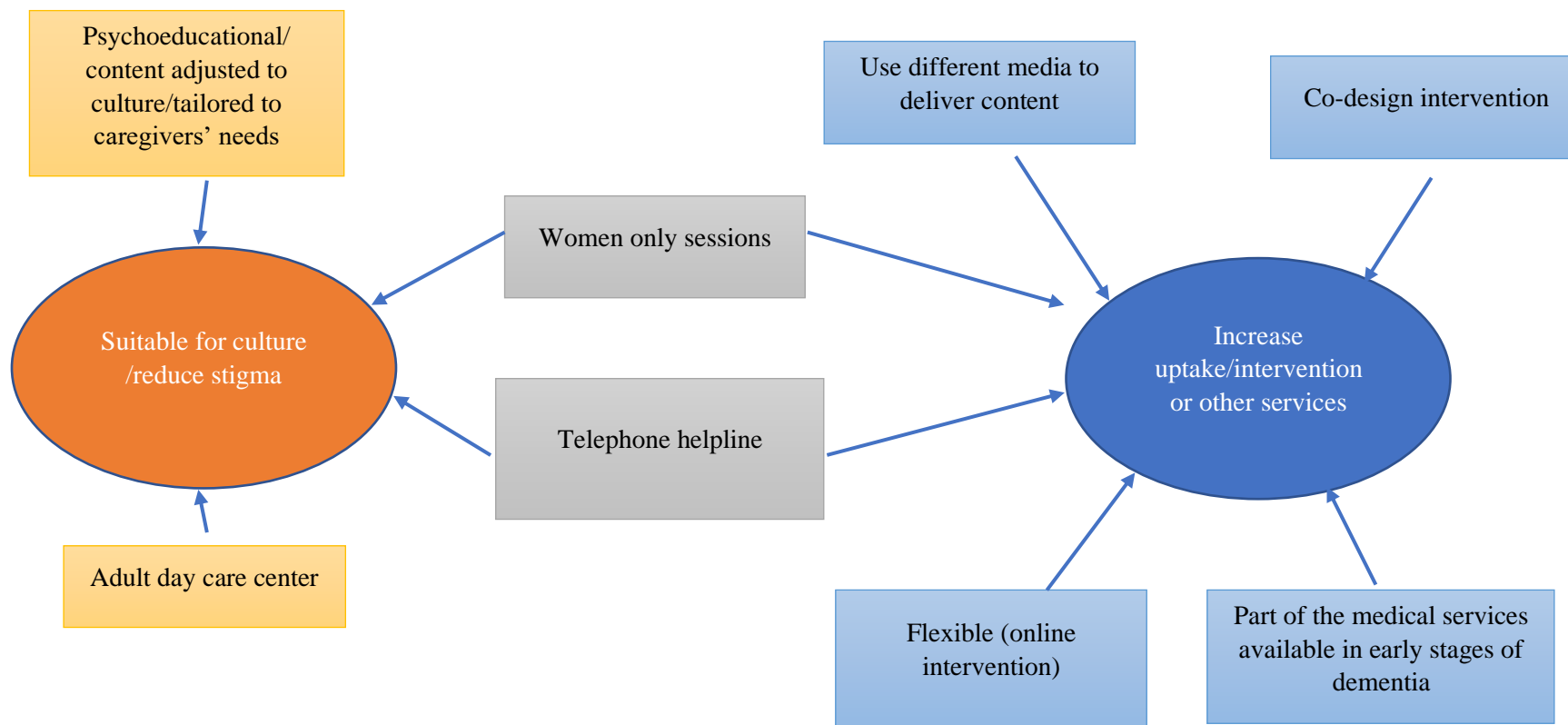
Context–Mechanism–Outcomes Configurations (CMOCs) and Middle Range Programme Theory

The number of studies identified and excluded at Stage 2 are shown in Figure 4 and Table 1 in Supplementary Material, 4.

Figure 4. Papers included from Stage 2 search for Phase 2
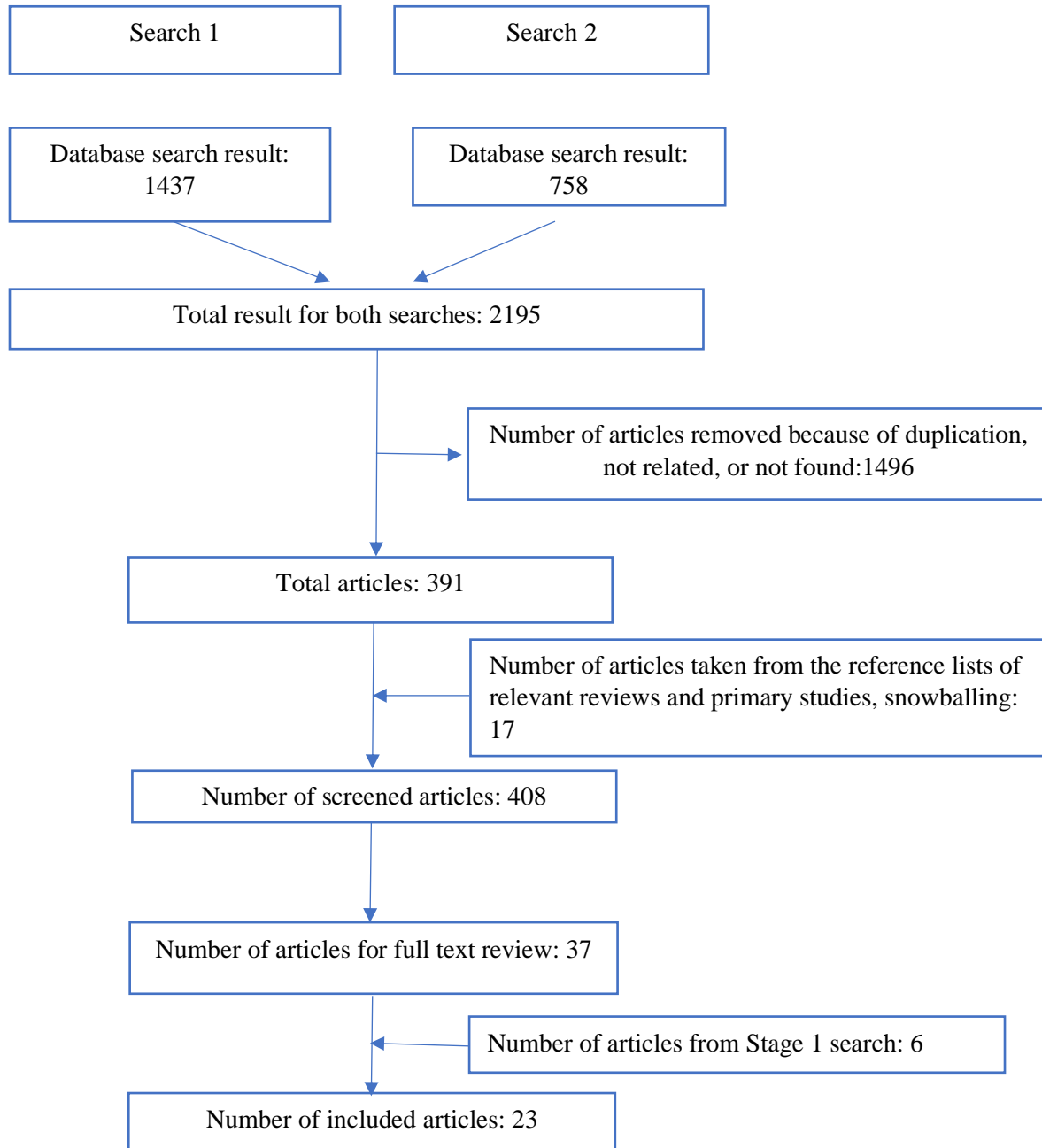
The evidence was used to develop eight CMOCs exploring the seven if…then statements (Table 2). These configurations were interrelated, representing key elements from the theories and their relationships with other factors. They show how and why interventions work and for whom. Each section includes quotations from the literature and interviews, followed by a context–mechanism–outcome configuration that provides an explanatory interpretation. Recurring patterns across the studies were discussed with CS and CH. Table 2 gives the if–then statements and shows how they were used to construct the CMOCs.

Table 2: Development from 'If… then' statements into CMOCs

Colour coding used to differentiate between context, mechanism, outcomes

If	Then	Evidence
If there were day care centres available in the MENA region, aligned with the region's cultural values, and reducing the stigma around asking for help for people living with dementia, where formal support was provided for their daily needs, including meals and medication, and involvement in therapeutic activities, such as cognitive stimulation therapy for a certain period throughout the day…	Then it would benefit both people living with dementia and informal caregivers. The informal caregivers could use the day care centre during the day to reduce their caring period and have time for themselves. At the same time, the person living with dementia would be in a safe environment that allows them to socialise and be involved in activities with others, which helps to decrease social isolation and enhance their communication skills, particularly in the early stages, which leads to a decrease in their use of medication and its side effects. It will minimise stress on informal caregivers and improve their mental and physical health.	Ghaffari et al. (2019) Tawfik et al. (2021) Interviews: S01, S05, S03, S07, S08

CMOC1 Adult Day Care Centres	Evidence
Informal caregivers are often responsible for providing in-home support with activities of daily living for people living with dementia, even when they have their own families or jobs to attend to. Accordingly, many of these caregivers can become overwhelmed and burned out because of the long hours and stress associated with caring for their family member with dementia, as well as from disruptions to their own sleep patterns. They are living in communities where there is a stigma associated with asking for help or leaving parents in nursing homes, which can lead to social isolation for both caregivers and those with dementia (context). To address these challenges, adult day care centres can be valuable resources for both informal caregivers and people living with dementia. This service allows the caregivers to keep the person they care for at home, while using these resources, because they are still responsible for the person they care for and this aligns with the cultural values of the region, reducing the stigma around asking for help. By using an adult day care centre, particularly in the early stages of dementia, caregivers can reduce the amount of time they spend caring for their family members with dementia and have time for themselves, with the availability of the transportation option. Meanwhile, the person living with dementia can receive food, medication, and contact with others and engage in therapeutic activities, such as cognitive stimulation therapy, and other activities that they might like(mechanism). This can improve the quality of life for caregivers and people living with dementia, and improve communication and reduce social isolation (outcomes).	de Bruin et al. (2021) Ryan (2021) Riley et al. (2014) Sun et al. (2022) Mukadam et al. (2015) Farina et al. (2020) Phillipson and Jones (2012) Velilla et al. (2022) Interviews S01, S08

If	Then	Evidence
If we provide informal caregivers with group sessions that are adjusted to suited the culture and tailored to caregivers' needs through brainstorming and taking feedback from them to enhance and co-design the sessions, which can include information about dementia, prevention, psychological education and how to deal with challenging behaviours, legal arrangements, how to deal with stigma, cognitive behavioural therapy (like stress management, coping with change and loss), skills and ways to improve the relationship with the person they care for…	Then informal caregivers will be able to express their feelings and needs and will be interested in attending the whole intervention, which leads to improving their management skills in dealing with changed behaviours with fewer medications. This reduces stress levels and enhances the quality of life of the person living with dementia and their caregivers.	Ghezelsefloo et al. (2019) Javadpour et al. (2009) Abdelzaher et al. (2022) Shata et al. (2017) Mahdavi et al. (2017) Tawfik et al. (2021) Interviews: S08, S06, S01
CMOC2 Collaborative Co-Design: Engaging Caregivers in Intervention Development		**Evidence**
Informal caregivers, with varying levels of education, often live in communities where there is a stigma around asking for help or leaving parents in nursing homes, leading to social isolation for those living with dementia. These caregivers are responsible for providing in-home support with daily activities for people living with dementia, despite having other responsibilities, such as caring for their own families or working, with little or		Javaid et al. (2021) Abdelzaher et al. (2022) Mukadam et al. (2015) Farina et al. (2020)

no support from other family members. This can lead to a point of feeling overwhelmed or burned out because of the long hours, stress, and lack of sleep associated with caring for someone with dementia, as well as dealing with changes behaviours (context). To address these challenges, informal caregivers can benefit from participating in face-to-face group sessions co-designed by themselves and healthcare professionals, such as psychiatrists, psychologists, or certified trainers. Through brainstorming with the caregivers and establishing their needs at the beginning of the programme (for planning the whole programme) or after each session (to plan the next one), it is possible to develop culturally appropriate and tailored content that meets the caregivers' needs. The sessions focus on increasing caregivers' knowledge about dementia, improving their skills in dealing with challenging behaviours, and providing a platform for caregivers to express their feelings and experiences through group discussions (mechanism). Leads to increased uptake of the intervention because caregivers feel engaged and heard. Participating in these sessions can help informal caregivers to enhance their management skills and improve the quality of life for both themselves and their family member who is living with dementia (outcomes).	Shata et al. (2017) Interviews: S01, S05
CMOC3 Empowering Caregivers: Collaborative Co-Design for Caregiver-Centred Interventions	**Evidence**
Informal caregivers, who are responsible for providing in-home support with daily activities for people living with dementia, despite having other responsibilities, such as caring for their own families or working, with little or no support from other family members. This can lead to a point of feeling overwhelmed or burned out because of the long hours, stress, and lack of sleep associated with caring for someone with dementia, as well	Morgan et al. (2019) Javaid et al. (2021) Lord et al. (2022) Molinari-Ulate et al. (2023)

as dealing with changes behaviours (context). To address these challenges, informal caregivers can benefit from participating in face-to-face group sessions co-designed by other caregivers, who take education seriously, and healthcare professionals, such as psychiatrists, psychologists, or certified trainers. Through brainstorming and caregivers' feedback, these sessions aim to develop culturally appropriate and tailored content that meets the caregivers' needs. The sessions focus on increasing caregivers' knowledge about dementia, improving their skills in dealing with challenging behaviours, and providing a platform for caregivers to express their feelings and experiences through group discussions (mechanism). This approach can produce interventions that are suitable for the culture and meet informal caregivers' needs, which leads to improved quality of life for both (outcomes).

Waugh et al. (2013)

Nielsen et al. (2022)

Mukadam et al. (2015)

Farina et al. (2020)

If	Then	Evidence
If the intervention includes face-to-face group interactions in a variety of ways, such as presentations, statistics, facts, pictures, videos, online, writing, and role-playing…	Then it will be suitable for caregivers with different literacy levels and will increase their confidence in the skills they have gained. This, in turn, will improve their ability to communicate with their family (including the person with dementia) and healthcare professionals.	Javadpour et al. (2009) Shata et al. (2017) Tawfik et al. (2021) Interviews: S01, S03, S04, S05, S06

CMOC4 Intervention Medium	Evidence
Informal caregivers with varying levels of education, and age are responsible for providing in-home support with daily activities for their family members living with dementia (context). Face-to-face group sessions use different mediums, such as illustrations, vignettes, role-playing, brainstorming, group discussion, and audio-visual aids to achieve various objectives. This approach makes the programme suitable for caregivers with different literacy levels and different learning styles. This increases caregivers' confidence in the skills they have gained, improving their ability to communicate with their family (including the person with dementia) and healthcare professionals (mechanism). Participating in these group sessions might increase caregivers' knowledge about dementia and improve their quality of life, without making them feel overwhelmed with information (outcomes).	Mukadam et al. (2015) Molinari-Ulate et al. (2023) Kim et al. (2021) Shata et al. (2017)

If	Then	Evidence
If caregivers were assessed from the beginning, alongside the person living with dementia (to determine their needs and mental health status), they could be enrolled in appropriate interventions, such as a compassion-based programme, day centre, psychoeducation, or multi-component intervention programme. These interventions could be integral components of neuropsychiatric services that are introduced to informal caregivers in the early stages of a diagnosis, when they are most needed and effective.	Then caregivers could learn necessary skills to deal with the situation and take care of themselves, including the importance of asking for help from other family members. This could be applied from the early stages of dementia, when non-pharmacological interventions can be effective, leading to a reduction in challenges associated with care and complications, an improvement in quality of life, and a decrease in care costs.	Abdelzaher et al. (2022) Jahani et al. (2022) Shata et al. (2017) Tawfik et al. (2021) Interviews: S01, S03, S04, S07, S08
CMOC5 Strategies to Increase Interventions Uptake		**Evidence**
Informal caregivers who bring their family member with dementia with early-stage dementia to the clinic for diagnosis or follow-up appointments are often unaware of how this will affect their lives (context). Informal caregivers can benefit from one-to-one consultations, education, and assessment of their own needs and mental health during follow-up appointments. This assessment could help them to enrol in appropriate non-pharmacological interventions, which can be integral components of neuropsychiatric services because they need more at this stage and feel lost. This can be effective during the early stages of dementia before they are		Velilla et al. (2022) Ducharme et al. (2014) Riley et al. (2014) Lohmeyer et al. (2021) Shata et al. (2017)

burned out (mechanism). By enrolling in these interventions, informal caregivers will be aware about how their family member's diagnosis will affect their lives and might absorb the information at this stage before they get overwhelmed by their caring responsibilities. This can reduce the challenges associated with care and complications, improve the quality of life for both themselves and the person living with dementia, decrease care costs associated with risk of complication, and ensure the continuity of the intervention (outcomes).

Jahani et al. (2022)

Interviews: S08, S03

If	Then	Evidence
If an online intervention option were available for caregivers to receive individual consultations from a multidisciplinary team, and they were trained in how to use it as well as how to support the assessment of the person living with dementia and recognise red flags that indicate the need for hospital care…	Then caregivers would be able to access it from home with the person they care for and include more than one caregiver who can receive a full assessment and plan from the multidisciplinary team in the same session. This will lead to reduced travel challenges and risks of complication that can arise from delayed or missed appointments. It would also facilitate early diagnosis, reduce the stigma associated with asking for help and support and provide a better management plan, especially when the medication can be used at an early stage. This, in turn, would reduce caregiver stress and improve their quality of life.	Javadpour et al. (2009) Noroozian & Mohammadian (2021) Interviews: S03, S04, S07, S08

CMOC6 Promoting Intervention Flexibility: Adapting to Caregivers' Needs	Evidence
Informal caregivers with higher education levels and people with cognitive impairments, including those living with dementia, are referred to the clinic for proper diagnosis, treatment, or follow-up (context). After the initial in-person visit, which includes a full assessment of people with dementia (cognitive assessment, mood, and activities) by pharmacological and non-pharmacological neuropsychological and neuropsychiatric interventions, they will be provided with health education about dementia and a customised management plan in discussion with the caregiver and person with dementia (based on the stage of dementia). They will then be introduced to telemedicine for online individual sessions that include both caregivers and the person with dementia that they can attend from home together. They will be shown how to use telemedicine, book appointments, and educated about red flags, such as when to call for follow-up or emergency care, and how to help with assessments from home (mechanism). This leads to improved quality of life for both caregivers and the person living with dementia, reducing the financial burdens and challenges associated with travel to in-person appointments. The opportunity to involve more than one caregiver in the care plan leads to a decreased load on one caregiver and this flexibility can prevent missed or delayed appointments that can lead to complications (outcomes).	Javaid et al. (2021) Sun et al. (2022) Mukadam et al. (2015) Melunsky et al. (2015) Moo et al. (2020) Noroozian & Mohammadian (2021) Interviews: S03, S04

If	Then	Evidence
If caregivers feel that someone is really trying to help them and available when they need to find solutions to	Then they will feel supported and able to get tailored advice to solve their problems. This could	Jahani et al. (2022)

the challenges they face (whether financial, cognitive, or psychological) associated with caring through a confidential helpline...	lead to decreased stigma associated with asking for help compared to asking in person, and decrease stress levels and risk of complications, and improve the quality of life for both parties. It could also increase the use of other medical services like face-to-face visits to support better diagnosis.	Interviews: S04, S03, S01, S07, S06
CMOC7 Enhancing other Services Uptake and Cultural Suitability		**Evidence**
Most informal caregivers for people living with dementia, often females, live in communities where there is a stigma associated with the diagnosis, making it difficult for them to ask for help (context). To help reduce the stigma associated with seeking help and diagnosis, caregivers can use a hotline, staffed by a healthcare professional, for reference and support purposes. This service offers confidentiality and compassion and allows caregivers to call from anywhere to receive help and support for themselves and how to deal with situations involving the person living with dementia, including strategies to cope with stress, identifying and preventing risk factors, and assessing mental health. Although the service aims to be available 24 hours a day, it requires high levels of human resources, which are still limited in some countries in the MENA region (mechanism). This leads to a decrease in caregivers' stress and complications associated with caring for the person living with dementia, and an increase in the uptake of other medical services, such as diagnostic clinics (outcomes).		Ryan (2021) Javaid et al. (2021) Heimerl et al. (2020) Sun et al. (2022) Hammad et al.(2022) Interviews: S03, S01

If	Then	Evidence
If we provide female caregivers of people living with dementia with interventions including women-only group sessions...	Then they will be able to participate freely in those sessions and share their experience with other caregivers. This can help them to build a support network and reduce their loneliness	Saadati et al. (2014) Javadpour et al. (2009)

CMOC 8 Empowering Female Caregivers	Evidence
Most informal caregivers for people living with dementia are female, living in communities where there is a stigma associated with the diagnosis and asking for help, which leads to them feeling alone and overwhelmed. (context). To help reduce the stigma associated with seeking help and diagnosis, they could participate in face-to-face women-only group sessions as it can be suitable for the culture, and they could feel comfortable and free to share their feelings and build a network of support with other female caregivers (mechanism). This might decrease their loneliness and improve their mental health (outcomes).	Saadati et al. (2014) Javadpour et al. (2009) Nielsen et al. (2022) Interviews: S01, S02, S03, S04, S05, S06, S07, S08

These CMOCs enabled the development of the middle range programme theory:

If the informal caregivers of people living with dementia are provided with suitable (culturally-tailored) interventions during and immediately after diagnosis, this will increase their knowledge about dementia and improve their management skills when they most need help and the stigma related to dementia diagnosis is higher, leading to improved quality of life for both people living with dementia and their informal caregivers.

Discussion

This review aimed to use a theory-driven realist approach to understand what interventions for informal caregivers of people living with dementia are likely to work in the MENA region, how, under what circumstances, and with what outcomes. As far as can be ascertained, this is the first realist review to explore interventions used by informal caregivers of people living with dementia in the MENA region.

Informal caregivers in the region could benefit from interventions reducing the stigma of asking for help with someone with dementia. This is especially true in the early stages of dementia, because of the high stigma associated with diagnosis. This could enable caregivers to enhance their coping skills before they become overwhelmed. Using evidence-based strategies with someone with dementia from an early stage can enhance communication skills and improve quality of life. Different types of interventions could support informal caregivers, including adult day care centres, and helplines. Some interventions could increase the uptake of other medical services. For example, in Qatar, access to a helpline increased referrals to and use of medical services. Other interventions could prevent complications associated with delays or missing appointments and enable caregivers to be supported by other family members (Noroozian & Mohammadian, 2021).

These interventions help reduce stress and improve the quality of life for both caregivers and people living with dementia. However, there is a shortage of healthcare professionals in the region, and many require training to enable them to better support informal caregivers and people living with dementia (S02, S06, S07; Barbarino et al., 2020; Halabi & Zafar, 2010; Javaid et al., 2021). Previous studies have recommended interventions for healthcare professionals to enhance their dementia-related knowledge and skills (Hattink, 2015; Shata et al., 2017).

This review has shed new light on some interventions. For example, an updated systematic review and meta-analysis about dementia caregivers found that they valued support groups, even though these had no major impact on any of the outcomes covered (Cheng et al., 2020). However, this realist review showed that face-to-face support groups were appreciated by caregivers because they decreased loneliness and provided a safe environment to vent. Interviewees reported that some caregivers continued to meet without

support from healthcare professionals, and that some caregivers never missed sessions. They had even considered asking caregivers to lead the group. Some women might also prefer female-only groups, and this should be explored further.

Caregivers in the MENA region experience a stigma associated with dementia and asking for help. They may therefore delay asking for help until they feel overwhelmed. By then, approaches like cognitive behavioural therapy may not be effective for someone living with dementia, which will lead to increased isolation. If appropriate interventions were offered to caregivers at an earlier stage (for example, as part of the diagnosis process), or as part of the services provided to families, this could decrease caregivers' stress and improve their skills in managing challenging behaviours. Providing interventions during later stages may be less helpful if caregivers are already overwhelmed. It is also important to consider community needs and cultural context in planning interventions.

Recommendations

This review recommends:

- Informal caregivers of people living with dementia need interventions that consider the appropriate cultural context.
- Informal caregivers who attend group and training interventions should contribute to session design.
- Providing advice on caring strategies using different delivery mediums can improve informal caregivers' management skills.
- Female caregivers might be more comfortable in female-only group interventions.
- A mixture of face-to-face and online sessions will probably work better for a wider range of informal caregivers.
- Interventions should address stigma and how to deal with or reduce it.
- Helplines can provide support for informal caregivers who have questions or need help caring for someone living with dementia.
- Organisations working with people living with dementia and their caregivers should promote the available interventions during the early stages of dementia or include them in the services available to families.

- Adult day care should be available for people in the early stages of dementia.
- Caregivers may have specific requirements for adult day care centres, especially around travel or accommodation.

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