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REVIEW



# The effectiveness of internet-based psychoeducation programs for caregivers of people living with dementia: a systematic review and meta-analysis

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## ABSTRACT

**Objective:** The objectives of this systematic review and meta-analysis were to identify the characteristics of internet-based psychoeducational programs for caregivers of people living with dementia and to synthesise program effectiveness.

**Method:** Five English databases and four Chinese databases were searched in June 2021 with no time limit applied. A narrative summary was performed to describe the characteristics of studies reviewed. Meta-analysis was applied to synthesise the pooled effects where data were available.

**Results:** A total of 14352 articles were identified from the database search and 19 were included in the final review. Interventions comprised educational, psychological, and behavioural training relevant to dementia care. Program duration ranged from 3 weeks to 12 months. Meta-analysis of 13 RCTs showed that internet-based psychoeducational programs had a significant effect on reducing caregivers' depressive symptoms (SMD  $-0.19$ ; 95% CI  $-0.03$ – $0.35$ ) and stress (SMD  $-0.29$ ; 95% CI  $-0.03$ – $0.54$ ). However, these programs did not show an effect on quality of life, anxiety, burden or self-efficacy in caregivers.

**Conclusion:** Internet-based psychoeducational programs can improve some aspects of caregivers' mental health and emotional wellbeing. The effects of programs on self-efficacy, anxiety, burden and quality of life for caregivers remain inconclusive.

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## KEYWORDS

Dementia; caregivers; psychoeducation; quality of life; depression; self-efficacy; caregiver burden; COVID-19

## Introduction


Dementia currently affects 55 million people worldwide and this number is projected to reach 152 million by 2050 (World Health Organization, 2021). Most people with dementia (PwD) are cared for by family caregivers at home (World Health Organization, 2021). It is well-researched that caring for PwD at home is physically stressful for caregivers due to the nature of the disease which requires 24-hour supervision, assistance with activities of daily living and management of a treatment regime for chronic conditions (World Health Organization, 2021). Caring for the PwD is also a source of psychological stress for caregivers (World Health Organization, 2021). Inability of caregivers to cope with physical and psychological stress contributes to their poor health, wellbeing and quality of life (QoL) (Farina et al., 2017). Psychoeducation is a major category of non-pharmacological interventions and is widely used to reduce caregivers' stress (Frias, Garcia-Pascual, et al., 2020). In this review, we describe the definition of psychoeducation as educational programs designed to improve caregivers' capabilities in providing daily care activities for people with dementia and in coping with stress (Cheng et al., 2020). This definition includes psychoeducation-a, or programs without mentioning psychological theories, and psychoeducation-b, or programs with psychotherapeutic components (Cheng et al., 2020).

Internet-based psychoeducation has been used increasingly in the past decade due to its flexibility and low costs (Egan

et al., 2018). The prolonged COVID-19 outbreak has interrupted most face-to-face education programs for caregivers, and internet-based psychoeducation has advantages for overcoming COVID-19 related challenges (World Health Organization, 2021). In this review, we considered the definition of internet-based education by Singh and Thurman (2019) and the definition of psychoeducation by Cheng et al. (2020). We describe the Internet-based psychoeducation for caregivers of PwD as an educational program that is (1) designed to improve caregivers' capabilities in providing daily care activities for PwD and in coping with stress; (2) delivered in an online environment using the Internet; (3) has flexible and accessible online learning activities without physical or virtual location restrictions (or asynchronous programs); and (4) may or may not have facilitators to interact with caregivers. Previous systematic reviews on internet-based interventions for caregivers were not specifically focused on psychoeducation but considered all types of interventions or did not undertake meta-analysis (Egan et al., 2018; Hopwood et al., 2018; Leng et al., 2020; Zhao et al., 2019). This systematic review and meta-analysis address this gap in the dementia care literature.

Psychoeducation for dementia caregivers is informed by stress and coping theories (Cheng et al., 2020; Frias, Garcia-Pascual, et al., 2020). Among various stress and coping theories, we found that the 'stress and health process' model described by Conde-Sala et al. (2010) was most relevant to this review as it explains the source of stress, negative impacts on caregivers

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and interventions (i.e. psychoeducation) that mitigate these negative impacts. This model was a combination of the stress process models introduced by Pearlin et al. (1990) and Schulz et al. (2002) which highlight the intervention effect on stressors (Conde-Sala et al., 2010). The 'stress and health process' model informed the design of program analysis and understandings about the relationships between sources of stress, effects on caregivers' health and wellbeing, and chosen outcomes. According to Conde-Sala et al. (2010), variables affecting caregiver health and wellbeing include caregiver contextual factors (i.e. ability to provide dementia care, family relationships, co-residing status, gender and time spent on care activities); care recipient factors or primary stressors (i.e. changed behaviours, dependence and multimorbidity); and other factors or secondary stressors (i.e. family conflict and financial difficulties). Interventions that can improve caregivers' symptoms of stress, such as anxiety, depression, isolation, burden and physical health, include non-pharmacological interventions (i.e. psychoeducation, social support and social resources) and treatment (i.e. pharmacological treatment) (Conde-Sala et al., 2010). Previous systematic reviews on the effectiveness of psychoeducation included all types of program delivery (i.e. face-to-face, telephone and internet-based delivery) (Cheng et al., 2020; Frias, Garcia-Pascual, et al., 2020). Systematic reviews on internet-based psychoeducation specifically are scarce. The lack of synthesis of research evidence in this increasingly demanding area of caregiver support may affect the development of evidence-based policy and practices.

Previous systematic reviews showed that dementia care education can mitigate caregiver contextual factors by equipping them with capabilities to effectively handle daily care activities and to develop positive thoughts towards dementia care (Jensen et al., 2015; Klimova et al., 2019). Studies also confirmed that dementia care education improved caregivers' self-efficacy (Easom et al., 2020). Dementia caregivers' self-efficacy is described as their belief that they can control upsetting thoughts, respond to changed behaviours and obtain respite care (Crellin et al., 2014; Steffen et al., 2002). Caregivers' self-efficacy is related to their QoL (Crellin et al., 2014; Farina et al., 2017). Based on these known relationships between dementia care education and outcomes on caregivers regarding contextual factors, a systematic review and meta-analysis needs to include self-efficacy and QoL of caregivers' and caregivers' responses to stressful care situations in the outcome measures.

The most commonly mentioned changed behaviours are apathy, confusion, agitation (i.e. wandering or vocal disruption) and depression (Perera et al., 2017; Pond et al., 2019). These are often associated with other factors besides physiological changes in the brain such as health and environment factors (i.e. comfort, inclusion, identity, attachment and occupation) (Cunningham et al., 2019; T. Kitwood, 1998; T. M. Kitwood & Kitwood, 1997). Although there is no consensus regarding the preferred terminology to describe this group of symptoms, there is general agreement that the language used needs to be dementia friendly (Wolverson et al., 2021). Therefore, consistent with view of the World Health Organization, we prefer to use the term 'changed behaviours' instead of medical terminology such as psychological and behavioural symptoms of dementia (BPSD) or neuropsychiatric symptoms in PwD (Burley et al., 2021; Wolverson et al., 2021).

In the 'stress and health process' model, changed behaviours are main primary stressors that contribute to caregiver stress and burden (Conde-Sala et al., 2010). Stress is described as the

caregivers' emotional reactions to challenging situations beyond their abilities and resources to cope (Conde-Sala et al., 2010), while burden is described as a subjective feeling of negative impact on caregivers' functioning (Williams et al., 2019). Caregiver burden can be conceptualised into objective burden (i.e. physical task due to the dependence of the PwD and the level of changed behaviours) and subjective burden (i.e. emotional distress due to caregivers' negative reactions to these behaviours) (Feast et al., 2016; Poon, 2019). Changed behaviours in PwD cause increased objective burden, and impact on family relationships and contributed to caregiver subjective burden (Conde-Sala et al., 2010; Williams et al., 2019). Up to 88% of PwD in community care settings showed changed behaviours (Poon, 2019). Yet, most caregivers showed limited knowledge about how to prevent and manage changed behaviours (Chiu et al., 2015). The relationship between primary stressors and caregivers' health and wellbeing indicates that the changed behaviours in PwD and caregivers' stress and burden need to be measured in a systematic review and meta-analysis.

Research shows that other primary stressors, such as PwD's physical and cognitive function decline, were directly associated with increased caregiver burden and the latter was associated with caregivers' anxiety and depressive symptoms (Armstrong et al., 2019; Morlett Paredes et al., 2017). Furthermore, other factors, such as social support, economic living standards, dyadic relationship factors and length of caring experience, also significantly correlated with carers' anxiety and depressive symptoms (Fekete et al., 2019; Watson et al., 2019). In other words, greater caregiver burden was associated with caregivers' psychological well-being measured as anxiety and depression.

Caregiver burden, carers' psychological well-being and carer's self-efficacy are all interrelated and directly linked to carers and care recipients' QoL (Farina et al., 2017; Holopainen et al., 2019). Caregivers with high self-efficacy is related to their beliefs that they have mastered certain skills to deal with challenges (Bandura, 1993; Steffen et al., 2002). WHO defines QoL as an individual's perception of their life expectations in the context of their culture and value systems (World Health Organization, 2020). Research shows caregivers of PwD reported worse health related QoL compared to non-PwD carers (Karg et al., 2018; Lippe et al., 2021). Caregivers self-perceived QoL is also linked to primary stressors such as the severity of PwD's condition, level of changed behaviours and other factors for example, level of social support caregivers received (Frias, Cabrera, et al., 2020; Pessotti et al., 2018).

Informed by the 'stress and health process' model described by Conde-Sala et al. (2010), the outcome measures for caregivers' psychological wellbeing in this review focused on anxiety, depression and caregivers' burden. In line with a previous systematic review, other outcome measures for QoL and self-efficacy were included as they directly or in-directly affect caregiver's health and well-being (Crellin et al., 2014). The review questions were: (1) what are the characteristics of internet-based psychoeducational programs for caregivers of PwD living at home? and (2) What is the effectiveness of internet-based psychoeducational programs for informal caregivers of PwD living at home?

## Methods

This review followed the Cochrane Handbook for systematic review of interventions (Higgins et al., 2021) and Preferred

Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021). The review protocol was registered with PROSPERO (registration number CRD42021 257562).

### Search strategies

The following English databases were searched: the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, Medical Literature Analysis and Retrieval System Online (Medline), the Cochrane Library and Scopus. The following Chinese databases were also searched: China National Knowledge Infrastructure (CNKI), Wang Fang Data, Weipu Data and Chao Xing Data. The search strategies are presented in [Supplementary material Appendix A](#). The search strategy was developed in line with the PICO framework, with no time limit applied. All key words were identified around online psychoeducation for informal caregivers of PwD and a Boolean search was conducted by combining the key words ([Supplementary material Appendix B](#)). A librarian was consulted for the database search.

### Inclusion and exclusion criteria

All interventional studies reflecting our operational definition of online psychoeducational programs for informal caregivers of PwD were included. Face-to-face or telephone delivered dementia education programs using digital video discs (DVD) or booklets were excluded. Synchronised online education, which mimics the physical classroom or DVD programs delivered through the Internet, were also excluded as this type of program showed little flexibility in program delivery and were often restrained by time and space. Studies were excluded if they were not reported in English or Chinese. The inclusion and exclusion criteria are presented in [Supplementary material Appendix C](#).

### Data collection process

All searched records were imported to Endnote 20 and Covidence, with duplicates removed (The EndNote Team, 2013; Veritas Health Innovation, 2021). Four reviewers (YY, LX, CM, SU) screened English titles and abstracts to identify whether a study met the inclusion criteria. Two reviewers (JW, JH) screened Chinese language titles and abstracts. After title and abstract screening, the reference list of each selected article was manually scanned. Full text papers were uploaded to Covidence to determine further eligibility by all reviewers (YY, LX, CM, SU screened English language articles and YY, LX, JW screened Chinese language articles). All reviewers met regularly to discuss and resolve any disagreements.

### Assessment of risk of bias

Risk of bias in the selected articles was assessed by two reviewers (YY, LX) according to the criteria recommended by the Cochrane Handbook (Higgins et al., 2021). Randomised Control Trials (RCTs) were assessed according to the Cochrane risk-of-bias tool (RoB2) (Higgins et al., 2021). This tool assesses bias arising from: (1) the randomisation process; (2) intervention deviation; (3) missing outcome data; (4) measurement of outcomes; and (5) selection of results. Each of these domains is

ranked for risk of bias as 'low', 'some concern' or 'high', with an overall assessment of study quality compiled.

Non-randomised studies were assessed according to ROBINS-I tool (Sterne et al., 2021). This tool assesses confounding, selection, information and reporting biases. The ROBINS-I tool provides a domain-level risk-of-bias judgement of 'low', 'moderate', 'serious' or 'critical', with an additional option for 'no information'. Two reviewers undertook an independent quality appraisal of the selected studies, with any disagreement resolved through consensus.

### Data extraction

A standardised Cochrane data extraction sheet was used to extract the following data: (1) author, publication, year and country; (2) participants' characteristics and sample size; (3) online psychoeducation or training details; (4) study setting, design and methods; (5) data collection time points, measurement tools and outcomes; and (6) main findings.

### Data synthesis and analysis

Characteristics of online psychoeducation components, outcomes of RCTs not suitable for meta-analysis and outcomes of non-RCTs were presented as a descriptive summary. Where appropriate, meta-analysis of results from included RCTs was undertaken using Review Manager 5.4.1 (RevMan) to estimate the effect of the program on care outcomes (The Cochrane Collaboration, 2014). The meta-analysis was also run through 'meta' package in R program by a second reviewer to ensure the robustness of results (Balduzzi et al., 2019). Authors of included RCTs were contacted to request original data when reported data was not suitable for meta-analysis. Heterogeneity, including samples and settings, and methodological heterogeneity was analysed prior to performing meta-analysis. Standardised mean differences (SMD) with a 95% confidence interval (CI) were calculated for continuous data. The statistical heterogeneity between studies was examined using  $I^2$  statistics. The results of included studies were pooled, and a random-effects model applied for studies that showed heterogeneity. Sub-group analysis was planned for studies that could be grouped into the following: programs with peer support, programs with a facilitator, or program duration of three months or six months. However, these subgroup analyses were not performed due to insufficient data in the results.

### Assessment of publication bias

We planned to test funnel plot asymmetry for publication bias, but this was not achievable due to the small number of RCTs identified.

### Assessment of evidence quality

The overall quality of evidence for each outcome was rated using the Grading of Recommendations Assessment, Development and Evaluation (GRADE, see [Supplementary material Appendix D](#)) (McMaster University and Evidence Prime, 2021). The GRADE system rates evidence at four levels: high quality, moderate quality, low quality and very low quality based on study limitations, result inconsistencies, indirectness, imprecision and reporting bias (Guyatt et al., 2008).



## Results

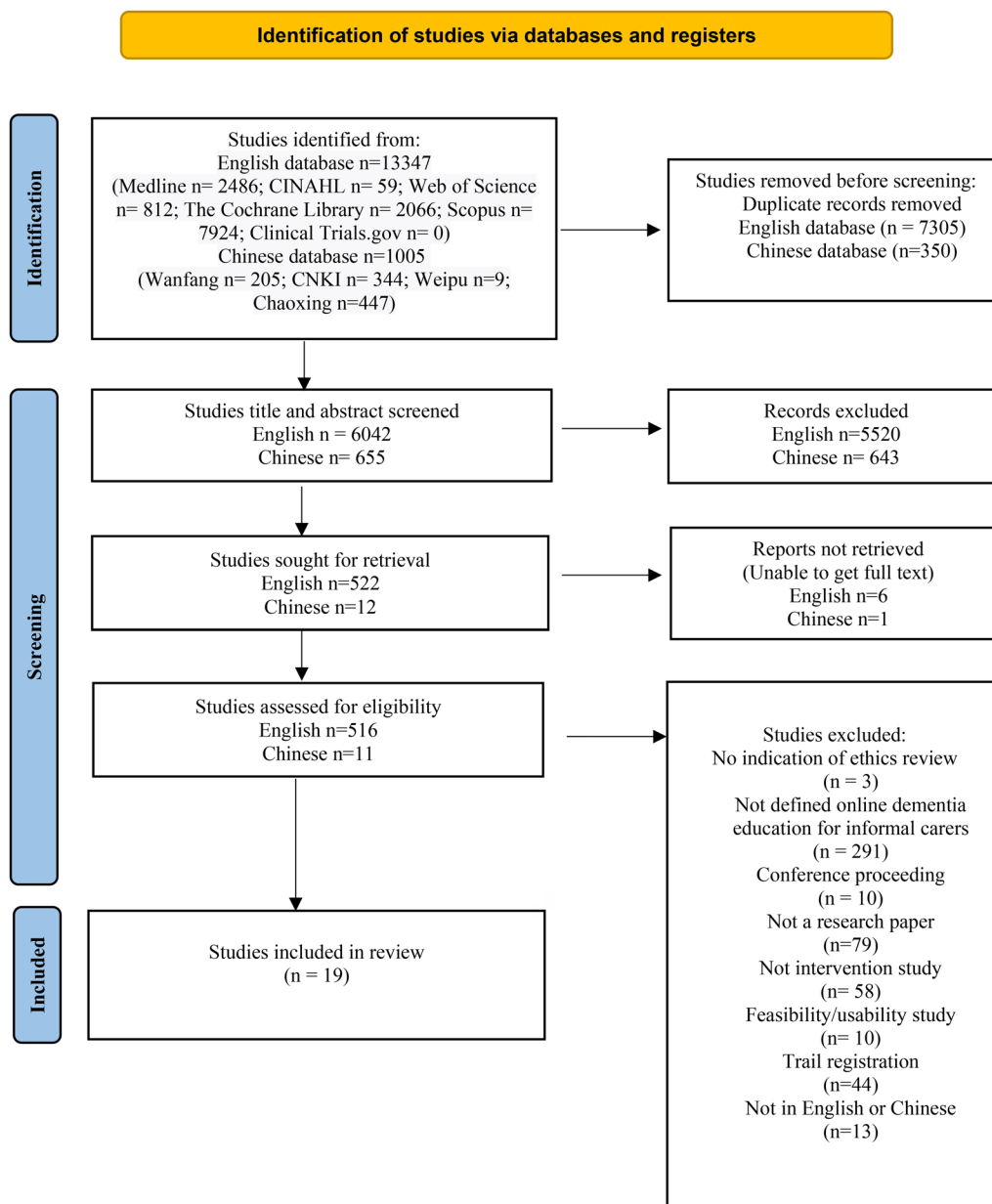
### Search process

A total of 14352 articles were identified (English language databases  $n=13347$ ; Chinese language databases  $n=1005$ ). Covidence automatically removed duplicates ( $n=7655$ ). A total of 527 (English language  $n=516$ , Chinese language  $n=11$ ) full text articles were retrieved after title and abstract screening (English language  $n=6042$ , Chinese language  $n=655$ ). After assessing the eligibility of full text articles, 19 studies written in English were included in this review. The study selection process is displayed in Figure 1.

### Risk of bias

All selected RCTs were assessed based on intention-to-treat effect and the assessment is displayed in [Supplementary material](#). Five out of 13 RCTs did not provide details of the randomisation process, and thus there is uncertainty about the allocation sequence and allocation concealment (Brennan et al.,

1995; Gustafson et al., 2019; Hicken et al., 2017; Kajiyama et al., 2013; Torkamani et al., 2014). All 13 RCTs had no significant baseline differences between intervention and control groups. Of the 13 RCTs, 10 interventions were not blinded to participants (Baruah et al., 2021; Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Hicken et al., 2017; Kajiyama et al., 2013; Metcalfe et al., 2019; Nunez-Naveira et al., 2016; Torkamani et al., 2014), while three RCTs were not blinded to researchers (Cristancho-Lacroix et al., 2015; Duggleby et al., 2018; Torkamani et al., 2014). All selected studies had a pre-formulated study protocol either through trial registration (Baruah et al., 2021; Blom et al., 2015; Boots et al., 2018; Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Kajiyama et al., 2013; Metcalfe et al., 2019) or ethics approval (Brennan et al., 1995; Duggleby et al., 2018; Gustafson et al., 2019; Hicken et al., 2017; Nunez-Naveira et al., 2016; Torkamani et al., 2014). The overall risk of bias assessment showed four RCTs to have some concerns (Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Hicken et al., 2017), while all other RCTs were considered to have low risk of bias. All non-RCT studies were assessed as low risk of bias (see [Supplementary](#)



**Figure 1.** Articles searching PRISMA flow diagram.

**Material).** Of 19 studies, 18 were funded through government grants.

### **Characteristics of selected studies**

No studies reported in the Chinese language met the selection criteria. Among the 19 selected studies, 13 were RCTs and six had a pre- and post- intervention design. Studies were conducted in the United States ( $n=6$ ), the Netherlands ( $n=4$ ), Canada ( $n=2$ ), France ( $n=1$ ), India ( $n=1$ ) and Iran ( $n=1$ ). Four studies were collaborations between European countries (Denmark, Poland and Spain  $n=1$ ; United Kingdom (UK), Spain and Greece  $n=1$ , France and Germany  $n=1$  and UK and the Netherlands  $n=1$ ). Selected studies are presented in Table 1.

All studies included participants who were informal caregivers of PwD. The average age of informal caregivers was between 50 and 70 years old. Most informal caregivers were female, with only two studies reporting a greater proportion of males to females (Baruah et al., 2021; Wijma et al., 2018). The relationship between informal caregivers and care recipients varied from spouse, parents/children, sibling to friends.

### **Characteristics of internet-based psychoeducational programs**

Among the 19 internet-based psychoeducational programs included in the review, six fully or partially utilised a theoretical framework to develop content (Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Duggleby et al., 2018; Hattink et al., 2015; Pleasant et al., 2017) (see Table 2). ComputerLink (USA), reported in 1995, was the earliest identified internet-based psychoeducation program for informal caregivers (Brennan et al., 1995). Of the 19 studies we reviewed, three are psychoeducation-a programs which had no psychological and behavioural training (Brennan et al., 1995; Hicken et al., 2017; Torkamani et al., 2014). The other 16 psychoeducational programs remain relatively similar with all setting out to cover theoretical, psychological and behavioural training relevant to dementia care with unlimited access to the website or information, and variable duration of 3 weeks to 12 months. Basic text-based internet functions such as information, discussion boards and email functions were used ubiquitously across all studies.

All programs had self-directed learning components, with eight programs using only basic functions (e.g. text-based information) (Baruah et al., 2021; Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Duggleby et al., 2018; Marziali & Garcia, 2011; van der Roest et al., 2010), and ten programs adding more complex components such as videos (Blom et al., 2015; Gaugler et al., 2015; Gustafson et al., 2019; Hattink et al., 2015; Hicken et al., 2017; Kajiyama et al., 2013; Metcalfe et al., 2019; Nunez-Naveira et al., 2016; Pleasant et al., 2017; Torkamani et al., 2014). A more recent program utilised virtual reality ( $n=1$ ) in addition to a website (Wijma et al., 2018). One program was delivered entirely through a telegram chat group by posting text based messages (Mollaei et al., 2021).

Some programs ( $n=9$ ) had functionality to facilitate interactive learning between caregivers and facilitators, and caregiver to caregiver (peer support). Interactive learning was incorporated in seven programs (e.g. iSupport program incorporated the interactive function of immediate feedback) (Baruah et al., 2021), while others offered recommendations to assist in service-related decision making (e.g. ComputerLink,

Dementia-Comprehensive Health Enhancement Support System [D-CHESS), STAR training portal and DEMentia-specific Digital Interactive Social Chart [DEM-DISC)) (Brennan et al., 1995; Gustafson et al., 2019; Hattink et al., 2015; van der Roest et al., 2010). Two programs offered an opportunity for reflection through the 'homework' function on the website (Kajiyama et al., 2013; Nunez-Naveira et al., 2016). An interaction function via a health questionnaire facilitated the detection and monitoring of health changes in informal caregivers and their care recipients (Torkamani et al., 2014).

Furthermore, seven programs offered interactions with facilitators or health professionals (Blom et al., 2015; Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Hicken et al., 2017; Mollaei et al., 2021) via the application (Blom et al., 2015), email (Boots et al., 2018), messaging (Gustafson et al., 2019), telephone (Hicken et al., 2017) or telegram group chat (Mollaei et al., 2021) utilising variations of two-way contact to provide information, guide discussions, provide feedback or deliver education content. Other programs were facilitated through passive techniques only, such as monitoring or moderating discussion forums (Brennan et al., 1995; Cristancho-Lacroix et al., 2015), or only answering questions if asked (Gustafson et al., 2019).

Peer support was facilitated in eight programs. While one program did not explain the type of social network used to support peer interaction (Nunez-Naveira et al., 2016), all other programs facilitated peer support through videoconferencing ( $n=1$ ) (Marziali & Garcia, 2011) or discussion forums ( $n=5$ ) (Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Marziali & Garcia, 2011; Torkamani et al., 2014). Private email was used in two programs to enable informal caregivers to contact each other (Brennan et al., 1995; Marziali & Garcia, 2011). The arrival of social media has changed people's communication and interactions significantly, yet only two programs utilised social networks, such as Facebook and LinkedIn, in addition to discussion forums to facilitate peer support (Hattink et al., 2015; Torkamani et al., 2014). One study reported using a telegram chat group for peer support meetings (Mollaei et al., 2021).

### **Characteristics of comparison groups**

Various comparisons were used in the 13 RCTs as detailed in the following. Five studies reported usual care as the comparison group (Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Metcalfe et al., 2019; Nunez-Naveira et al., 2016; Torkamani et al., 2014). Two studies reported usual care plus additional support (i.e. non-frequent counselling or local service training) as the comparison group (Boots et al., 2018; Brennan et al., 1995). Alternative educational information was provided to the comparison group in four studies through a booklet (Baruah et al., 2021; Duggleby et al., 2018; Gustafson et al., 2019; Hicken et al., 2017), in one study via a website (Kajiyama et al., 2013) and in one study via email bulletins (Blom et al., 2015).

### **Meta-analysis**

#### **Caregiver's QoL**

Six RCTs were included in the meta-analysis of the effectiveness of online psychoeducational programs on caregiver's QoL (Baruah et al., 2021; Boots et al., 2018; Hattink et al., 2015; Kajiyama et al., 2013; Metcalfe et al., 2019; Torkamani et al.,

**Table 1.** Characteristics of selected studies.

| Author<br>Year<br>Country                     | Study design   | Settings                     | data collection time | Participants   | Intervention  | Comparison   | Outcome measure (instrument)   | Main findings   |
|---|--|------------------------------|----------------------|--|---|--|--|---|
| S01<br>Baruah et al. (2021)<br>India          | RCT<br>Data collection:<br>Baseline<br>3 months  | India wide                   |                      | Informal caregiver of PwD,<br>>18yrs old, live in India,<br>access to internet<br>Sample size= 55<br>IG = 29, CG =26<br>Mean age =46.5<br>Males =54%                 | iSupport Online<br>dementia education<br>program  | Education only<br>e-book on<br>brochure  | Primary outcomes<br>Caregiver burden (ZBI [score 0-88, ↓ =better])<br>Depression (CES-D10 [score 0-30, ↓ =better])<br>Secondary outcomes<br>Person centred attitude (ADQ: [score 18-90, ↑ =better])<br>Self-efficacy (RIS Eldercare Self-efficacy; PMS [score 7-35, ↑ =better])<br>QoL (EuroQoL Visual Analog Scale [score 0-100, ↑ =better])  | No significant difference in caregiver burden, depression, self-efficacy and QoL.<br>Significant higher positive attitude towards dementia in the IG.<br>Poor education program engagement                    |
| S02<br>Blom et al. (2015)<br>The Netherlands  | RCT<br>Data collection:<br>Baseline<br>3 months<br>6 months  | Netherlands wide recruitment |                      | Informal caregiver of PwD,<br>who has some symptoms<br>of depression or care<br>burden<br>Sample size = 175<br>IG = 90, CG = 85<br>Mean age = 61.2<br>Female = 69.4% | Mastery over dementia<br>online lessons   | E- bulletins sent by<br>email every<br>3 weeks                                     | Primary outcomes<br>Depression (CES-D 20 [score 0-60, ↓ =better])<br>Secondary outcome<br>Anxiety (HAD [score 0-21, ↓ =better])<br>Additional measures for imputation<br>Self-perceived stress (SPPIC [score 0-9])<br>Caregiver's stresses relate to PwD behaviour (RMBPC [score 0-16])<br>Caregiver competency (SSCQ [score 0-7]; PMS [score 0-20])   | Caregivers' anxiety and depression significantly decreased in IG<br>High dropout rate   |
| S03<br>Boots et al. (2018)<br>The Netherlands | A single-blind RCT<br>2 clinics in South of Netherlands<br>Data collection:<br>Baseline<br>8 weeks             |                              |                      | Informal caregivers of PwD,<br>access to the Internet at<br>home, basic computer<br>skills,<br>Sample =68<br>IG = 31, CG = 37<br>Mean age = 67.8<br>Female = 65%     | Partner in Balance (PIB):<br>4 self-paced<br>web-based modules<br>Email or telephone<br>feedback from<br>coach over 8 weeks | Usual care waiting list<br>group -<br>nonfrequent<br>counselling                   | Primary outcomes<br>Self-Efficacy (CSES: management self-efficacy [score 4-40, ↑ =better], service use self-efficacy [score 5-50, ↑ =better])<br>Depression (CES-D20 [score 0-60, ↓ =better])<br>Secondary outcomes<br>Anxiety (HADS-Anxiety [score 0-21, ↓ =better])<br>Competency (PMS [score 7-35, ↑ =better])<br>QoL (CECAP-O) [score 0-1, ↑ =better]<br>Stress (PSS [↓ =better])                      | Improvement in self-efficacy, service use self-efficacy, mastery and QoL; No differences in caregiver depression, anxiety, and stress.  |
| S04<br>Brennan et al. (1995)<br>USA           | RCT<br>Alzheimer's disease research registry and local support group<br>Data collection: Baseline<br>12 months |                              |                      | Informal caregivers of PwD,<br>telephone connection, can<br>read and write English<br>Sample size 96<br>IG = 47, CG = 49<br>Mean age= 64<br>Female = 67%             | ComputerLink<br>Monthly phone call<br>Over 12 months  | Usual care, received<br>placebo training<br>for local service<br>and care provider | Primary outcome-not specified<br>Decision making confidence<br>(Modified decision confidence scale [↑ =better])<br>Decision making skill<br>(self-report instrument)<br>Perceived social support<br>(The instrumental and Expressive Social Support Scale [↑ =better])<br>Additional measures<br>Caregiver burden (Impact of caregiving scale [↓ =better])<br>Depression (CES-D20 [score 0-60, ↓ =better]) | Increase in caregivers' decision-making confidence. No effect on decision making skills and caregivers' social isolation.<br>Average program access was 2 days a week, using discussion forum more than email |

(Continued)

**Table 1.** Continued.

| Author<br>Year<br>Country                            | Study design settings data collection time   | Participants  | Intervention  | Comparison   | Outcome measure (instrument)   | Main findings  |
|--|--|---|---|--|--|--|
| S05<br>Cristancho-Lacroix<br>et al. (2015)<br>France | Non-blinded RCT<br>A day care centre geriatric unit in Paris<br>Data collection:<br>Baseline<br>3 Months<br>6 Months   | Informal caregiver of PwD,<br>French speaking, PSS > 12,<br>internet access<br>Sample size = 49<br>IG = 25, CG = 24<br>Mean age = 64.2<br>Female = 64%  | The Diapason program  | Usual care provided<br>with information<br>about the illness<br>during semi-<br>annual follow-up<br>with their<br>geriatrician           | Primary outcome<br>Stress (PSS-14 [score 0-56, ↓ = better])<br>Secondary outcomes<br>Depression (BDI-II [score 0-63, ↓ = better])<br>Caregiver burden (ZBI [score 0-88, ↓ = better])<br>Self-efficacy (RSCS [score 0-100, ↑ = better])<br>Caregiver's stress related to memory and behaviour<br>problems (RMBPC- reaction [2 subscale, frequency<br>and caregiver strain, score 0-4, ↓ = better])<br>Self-perceived health (NHP [score 0-100, ↑ = better])<br>Self-rating visual analog scale: 1) knowledge about<br>Alzheimer's disease 2) overall stress, 3) self-efficacy<br>for coping 4) quality of relationship [score 0-100,<br>↑ = better] | No significant difference in<br>stress, coping, and<br>self-perceived health.<br>Significant change in<br>dementia knowledge.<br>Average use of website 19.72<br>times, most visited within<br>3 months was the forum,<br>after 3 months the<br>connection times were<br>near zero |
| S06<br>Duggleby et al.<br>(2018)<br>Canada           | Pragmatic RCT<br>Local Alzheimer's Society and carer support groups<br>in Ontario and Alberta<br>Data collection: baseline, 1 month, 3 months, and<br>6 months | Informal caregiver of PwD,<br>>18 years old, caring for a<br>person aged 65 years or<br>older living with PwD and<br>MCI in the community,<br>valid email address and<br>access to a computer<br>Sample size = 199<br>IG = 101, CG = 98<br>Age (Mean) = 63.6<br>SD = 11.6<br>Female = 80.9% | My Tools 4 Care (MT4C)  | Educational control<br>group received a<br>copy of 'The<br>Progression of<br>Alzheimer's<br>Disease' booklet<br>(Alzheimer's<br>Society) | Primary outcome<br>Health related QoL (SF-12 v2: mental health component [score 0-100, ↑ = better])<br>Secondary outcomes<br>Health related QoL (SF-12 v2: physical health component [score 0-100, ↑ = better])<br>Self-efficacy (GSES [score 10-40, ↑ = better])<br>Hope (HHI [score 12-48, ↑ = better])<br>Cost analysis (HSSUI)   | No significant group<br>differences were observed<br>in the primary or<br>secondary outcome<br>measures.<br>73% participants used<br>website once over<br>3 months.  |
| S07<br>Gustafson et al.<br>(2019)<br>USA             | RCT<br>The Wisconsin Alzheimer's Disease Research Center<br>Data collection: baseline<br>2, 4 and 6 months   | Informal caregiver of PwD, live<br>with care recipient, can<br>read English<br>Sample size = 25<br>IG = 14, CG = 11<br>Age = 55-75<br>Female = 61%  | Dementia<br>Comprehensive<br>Health<br>Enhancement<br>Support System<br>(D-CHESS) website | A caregiving<br>handbook   | Primary outcome-not specified<br>Caregiver burden (A caregiver load scale [score 0-10,<br>↓ = better])<br>Depression (Patient Health Questionnaire [↓ = better])<br>family conflict (family conflict on a 4-point Likert scale<br>[average score ↓ = better])<br>Care decision (the Satisfaction with Decision Scale<br>[↑ = better])<br>Social support (MOS Social Support Survey [↑ = more<br>support])<br>Loneliness (UCLA Loneliness Scale [↑ = more loneliness])<br>Anxiety (The Generalized Anxiety Disorder scale [score<br>0-10, ↓ = better])<br>Coping competence (Caregiver appraisal scale<br>[↑ = better])                             | IG showed better results in<br>social support, anxiety,<br>loneliness, and coping<br>competence, no difference<br>on caregiver burden,<br>decision satisfaction and<br>depression. Show worse<br>result in family conflict.  |

(Continued)



Table 1. Continued.

| Author<br>Year<br>Country                                | Study design settings data collection time  | Participants   | Intervention   | Comparison   | Outcome measure (instrument)  | Main findings   |
|--|---|--|--|--|---|---|
| S08<br>Hattink et al. (2015)<br>The Netherlands &<br>UK  | RCT<br>The Netherlands: meeting centres and Alzheimer's organisations' regional branches; UK: Caregivers' cafes and groups in the community.<br>Data collection: baseline<br>2-4 months post intervention | Informal caregivers, volunteers and formal carers<br>Sample size = 142<br>Netherlands = 85 (informal carer = 59)<br>UK = 57<br>(Informal carer = 22)<br>Informal carers:<br>IG = 27, CG = 32<br>Informal caregivers mean age = 52.93<br>Female = 74% | STAR training portal   | Usual care   | Primary outcomes<br>Knowledge on dementia (ADKS) [score 1-30, ↑=better]<br>Attitudes toward dementia (the Alzheimer's disease survey [Hope scale score 8-40; person scale score 10-50, ↑=better]; the Approaches to Dementia Questionnaire (ADQ) [score 18-90, ↑=better])<br>Secondary outcomes<br>Empathy (the Interpersonal Reactivity Index) [4 sub-scale, score 0-28, Distress: ↓=better, Empathy: ↑=better, Fantasy: ↑=better, Perspective: ↑=better]<br>Competence (SSCQ) [score 0-7, dichotomizing by only counting value of 4 or 5, ↓=better]<br>QoL (2 questions rate 1-10) [score 1-10, not clear]<br>Burden (1 question) [score 1-5, not clear]<br>Primary outcome-not specified<br>Caregiver burden (ZBI Scale [score 0-48, ↓=better])<br>Caregiver grief (Caregiver Grief Inventory-Short Form [↓=better])<br>Depression (PHQ [↓=better])<br>Family conflict and hardship (2 questions [↓=better])<br>Nursing home placement (The Desire to Institutionalize Scale [↓=better]) | For informal caregivers, there is significant improvement in attitude towards dementia, IG reported less distress, decrease in self-reported competence.  |
| S09<br>Hicken et al. (2017)<br>USA                       | RCT<br>Multisite in the community<br>Data collection:<br>Baseline<br>4 months, 6 months   | Informal caregivers of PwD<br>Sample size = 155<br>IG = 77, CG = 78<br>Mean age = 71.6<br>Female = 90%   | Electronic intervention  | The telephone support group received printed educational material adapted from prior caregiver interventions and a DVD that included content identical to the electronic formats | Primary outcome-not specified<br>Stress (PSS-10 [↓=better])<br>Level of bother due to behaviour issue (RMBPC-reaction [↓=better])<br>Depression (CES-D [score 0-60, ↓=better])<br>QoL (Perceived quality of life-19 items [↑=better])   | No significant outcome difference   |
| S10<br>Kajiyama et al. (2013)<br>USA                     | RCT<br>Family service agencies in the community<br>Data collection: 3 months post intervention  | Informal caregivers of PwD,<br>>21 years old, access to internet, CES-D < 30,<br>engage in care > 8 h week<br>Sample size = 103<br>IG = 46, CG = 57<br>Mean age = 56.12<br>Female = 87%  | The iCare program<br>Available for purchase                    | Educational website containing similar information about dementia but without skills to deal with stress from caregiving.  | Primary outcome-not specified<br>Stress (PSS-10 [↓=better])<br>Level of bother due to behaviour issue (RMBPC-reaction [↓=better])<br>Depression (CES-D [score 0-60, ↓=better])<br>QoL (Perceived quality of life-19 items [↑=better])   | Significant change in perceived stress for the IG.<br>No changes in other outcomes.<br>IG's average time spend on website = 6.42 times/month; 78% IG applied new knowledge in their caregiving situation. |
| S11<br>Metcalfe et al. (2019)<br>UK, France &<br>Germany | Unblinded RCT<br>Memory clinics in Germany and France, not-for-profit organisations in UK<br>Data collection:<br>Baseline, week 6, week 12  | Informal caregivers of PwD,<br>>18 years old, PwD has onset of symptom before 65 yrs, basic computer skills and literacy<br>Sample size = 70<br>IG = 39, CG = 31<br>Mean age = 57.6<br>Female = 60%  | RHAPSODY project<br>in English, French, German, and Portuguese | Waiting list control group   | Primary outcome-not specified<br>Self-efficacy (Revised Scale for Care-giving Self-Efficacy [score 0-100, ↑=better])<br>Stress (PSS-10 [↓=better])<br>Burden (BSFC [↓=better]); RMBPC-reaction [↓=better])<br>Health (EQ-5D-5L) [score 0-100, ↑=better]   | Significant change in IG in stress and caregiver reaction to disturbing behaviour.<br>No significant differences in caregiving self-efficacy, caregiver burden or health related quality of life.         |

(Continued)

**Table 1.** Continued.

| Author<br>Year                        | Country                       | Study design settings data collection time   | Participants  | Intervention   | Comparison  | Outcome measure (instrument)  | Main findings   |
|---------------------------------------|-------------------------------|--|---|--|---|---|---|
| S12<br>Nunez-Naveira<br>et al. (2016) | Denmark,<br>Poland &<br>Spain | RCT<br>Local Alzheimer's associations of adult day care<br>centres<br>Data collection:<br>Baseline<br>3 months       | Informal caregivers of PwD<br>who lives in Denmark,<br>Poland or Spain, literate,<br>suffering burden according<br>to ZBI, provided care for at<br>least 6 weeks without<br>remuneration<br>Sample size = 61<br>IG = 30, CG = 31<br>Age: NI<br>Female = 63.9% | UnderAID application<br>accessed via<br>internet connected<br>mobile phone,<br>tablet or PC  | Usual care  | Primary outcome-not specified<br>Care burden (ZBI [score 0-88, ↓=better])<br>Depression (CES-D [score 0-60, ↓=better])<br>Competence (the Caregiver Competence Scale [score<br>0-16, ↑=better])<br>Caregiver satisfaction (the Revised Caregiving<br>Satisfaction Scale [score 0-30, ↑=better])   | Significant decrease in<br>depressive symptoms in<br>IG; no change in other<br>outcomes   |
| S13<br>Torkamani et al.<br>(2014)     | UK<br>Spain &<br>Greece       | RCT<br>Hospital outpatient clinics<br>Data collection: baseline, 3 months, and 6 months                              | Informal caregiver of PwD and<br>care recipients with<br>moderate to mild cognitive<br>impairment<br>Sample size = 37<br>IG = 17, CG = 20<br>Mean age = 60.69<br>Female = 45%   | A technology platform<br>for the Assisted<br>Living of Dementia<br>eDeryl (Individuals<br>and their carers'<br>(ALADDIN))  | Usual care  | Primary outcome-not specified<br>Caregiver burden (ZBI [score 0-88, ↓=better])<br>Neuropsychiatric Inventory (NPI) [score 0-100, ↓=better]<br>Depression<br>BDI [score 0-63, ↓=better]<br>Zung Depression Self-Rating Scale [score 20-80,<br>↓=better]<br>QoL (EuroQoL [score 0-100, ↑=better]; Quality of Life<br>Scale [score 16-112, ↑=better])  | IG showed decrease burden<br>and improvement in<br>quality of life. No<br>statistically significant<br>difference in depression<br>symptoms. However, IG<br>participants reported<br>fewer depressive<br>symptoms compared to<br>CG.  |
| S14<br>Gaugler et al.<br>(2015)       | USA                           | Pre and post intervention test<br>Multiple sites in the community<br>Data collection: NI                             | Informal caregivers of PwD<br>(living at home or an assist<br>facility), access to internet<br>Sample size= 41<br>Mean age =58.2<br>Female =90.2%   | The CARES for Families   | N/A   | Primary outcome-not specified<br>Knowledge on dementia (Dementia Care Knowledge- 20<br>item)  | 81.5% (n = 33) indicated a<br>gain in dementia<br>knowledge   |
| S15<br>Marzali and Garcia<br>(2011)   | Canada                        | Quasi experimental study<br>Clinics and community services agencies<br>Data collection:<br>Baseline<br>6 months      | Informal caregivers of PwD<br>Sample size = 91<br>IG = 40; CG = 51<br>Age (mean)=65.51  | Caring for Me (CFO)<br>password protected<br>website and training<br>manuals<br>Education video x 6<br>Online chat group<br>intervention<br>Available in English and<br>French | Access to all website<br>features except<br>educational<br>videos<br>Weekly online<br>meeting for 1 h for<br>20 weeks | Primary outcome-not specified<br>Neuroticism<br>(The Eysenck Personality Questionnaire Revised)<br>Self-efficacy (RSCS [score 0-100, ↑=better])<br>Social support (MSPSS [↑=better])<br>Health (the Health Status Questionnaire [score 0-100,<br>↑=better])<br>Depression (CES-D [score 0-60, ↓=better])<br>Stress relates to PwD (SMAF [↓=better]) | Both groups showed<br>significant improvement in<br>self-efficacy.<br>The IG showed significantly<br>greater improvement in<br>mental health, lower<br>distress scores associated<br>with managing the care<br>recipient's deterioration in<br>cognitive function and<br>improved social support<br>IG showed significant<br>improvement in wellbeing |
| S16<br>Mollaei et al. (2021)          | Iran                          | Pre and post test<br>Memory clinic of Taleghani hospital in Tehran<br>Data collection: baseline<br>Post intervention | Informal caregivers living with<br>PwD over 1 year, literate,<br>can use messenger<br>network, wellbeing score<br><52<br>Sample size = 86<br>IG = 43, CG = 43<br>Mean age =51.95<br>Female = 75%  | Education message via<br>telegram channel  | Usual care  | Primary outcome-not specified<br>Well-being (The World Health Organization's 5-question<br>well-being questionnaire [↑=better])   | IG showed significant<br>improvement in wellbeing   |

(Continued)

Table 1. Continued.

| Author<br>Year   | Country | Study design settings data collection time  | Participants  | Intervention   | Comparison | Outcome measure (instrument)   | Main findings   |
|--|---------|---|---|--|------------|--|---|
| S17<br>Pleasant et al.<br>(2017)<br>USA                  |         | Pre and post test<br>Existing consumers of CARES® in Oregon and<br>Oregon Health Care Association<br>Data collection:<br>Baseline,<br>30 days post intervention | Informal and formal caregivers<br>Sample size = 51<br>Mean age = 51<br>Female = 88%   | CARES® Dementia<br>Basics online<br>program                              | N/A        | Primary outcome-not specified<br>Knowledge (The 16-item dementia-based knowledge<br>questionnaire)<br>Competency (The Sense of Competence in Dementia<br>Care Staff Scale)   | Significant but modest<br>improvement in<br>dementia-specific<br>knowledge at both<br>post-test and 30-day<br>follow-up test  |
| S18<br>van der Roest et al.<br>(2010)<br>The Netherlands |         | Pre and post test<br>Meeting centres, day care facility, memory clinics<br>and a support organisation in Amsterdam<br>Data collection:<br>Baseline<br>2 months  | Informal caregivers of PwD in<br>the community, familiar<br>with computer and<br>internet,<br>Sample size = 28<br>IG = 14, CG = 14<br>Mean age = 60.2<br>Female = 78%   | DEMENTIA-specific<br>Digital Interactive<br>Social Chart<br>(DEM-DISC)   | Usual care | Primary outcome<br>Need (The Camberwell Assessment of Need for the<br>Elderly)<br>Competency (SSCQ,<br>PMS [score 7-35, ↑=better])<br>Secondary outcome<br>QoL (Quality of Life Alzheimer's Disease scale)   | IG reported more met needs<br>at post-test, higher feeling<br>of competence, no<br>difference found for<br>quality of life and carer<br>knowledge.<br>On average participants<br>accessed 5.14 times, mean<br>duration is 14:36 min. The<br>most consulted questions<br>were about the<br>consequences of dementia<br>and support for practical<br>problems |
| S19<br>Wijma et al. (2018)<br>The Netherlands            |         | Pre and post-test,<br>4 different care institutes in central and southern<br>regions of The Netherlands.<br>Data collection<br>1 weeks prior and 3 weeks after  | Informal caregivers of PwD at<br>home, Dutch speaking, no<br>visual or hearing<br>impairment and familiar<br>with computer.<br>Completed pre-test = 42<br>Watched movie = 42<br>Completed post-test = 35<br>Mean age = 55.1<br>Female = 40% | Through the D'mentia<br>Lens (TDL)- 360°<br>simulation movie<br>e-course | N/A        | Primary outcome<br>Attitude towards dementia (ADQ 'perspective-taking'<br>(PT) subscale of the Interpersonal Reactivity Index)<br>Secondary outcomes<br>Self-perceived pressure (SPPIC)<br>Self-efficacy (the 'Trust in Own Abilities'<br>Relationship (the Dyadic Relationship Scale) | Significantly improved in<br>empathy, confidence in<br>caring for the person with<br>dementia and positive<br>interactions with the<br>person with dementia.  |

Note. IG = intervention group; CG = control group; EQ-5D-5L = A standardised measure of health status in five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) used in health-economic analyses to indicate health-related quality of life and calculate quality-adjusted life years (QALYs); N/A = not applicable; NI = not indicated; PwD = People living with dementia; MCI = mild cognitive impairment; RCT = randomised control trial.

**Table 2.** Content of psychoeducational programs and relations to the 'stress and health process' (SHP) model.

| Program/Study  | Duration                   | Content  | Theoretical training | Psychological training | Behaviour training | Facilitator | Peer support | Theoretical framework  | Relations to the SHP model                                  |
|--|----------------------------|--|----------------------|------------------------|--------------------|-------------|--------------|--|---|
| iSupport (Baruah et al., 2021)                         | 3 months, unlimited access | 23 lessons with completion of 5 self-directed lessons recommended, relaxation exercise at the end of each lesson. Focus on skill training  | yes                  | yes                    | yes                | no          | no           | no   | Caregiver factors and care recipient factors                |
| Mastery over dementia (Blom et al., 2015)              | 6 months unlimited access  | 8 internet lessons covering problem solving, relaxation, arranging help from others, cognitive restructuring and assertiveness training  | yes                  | yes                    | yes                | yes         | no           | no   | Caregiver factors, care recipient factors and other factors |
| Partner in Balance (Boots et al., 2018)                | 8 weeks                    | 4 self-paced web-based modules<br>Email or telephone feedback from coach   | yes                  | yes                    | yes                | yes         | no           | no   | Caregiver factors, care recipient factors and other factors |
| ComputerLink (Brennan et al., 1995)                    | 12 months                  | Content covers information, decision support and communication   | yes                  | unclear                | unclear            | yes         | yes          | Multi-attribute utility theory   | Caregiver factors   |
| The Diapason program (Cristancho-Lacroix et al., 2015) | 3 months                   | A free password-protected website, 12 thematic sessions, each session 15-30 min. covers dementia care knowledge  | yes                  | yes                    | yes                | no          | yes          | Cognitive theories of stress; Bandura's self-efficacy model                                | Caregiver factors, care recipient factors and other factors |
| My Tool 4 Care (Duggleby et al., 2018)                 | 3 months                   | Each web page contains frequently asked questions, resources and a calendar. Includes an electronic copy of the Alzheimer Society's 'The Alzheimer's Disease' booklet  | yes                  | yes                    | yes                | no          | no           | Meleis' theory of transition   | Caregiver factors, care recipient factors and other factors |
| D-CHESS (Gustafson et al., 2019)                       | 6 months                   | A website for use on computers or tablets; Covers information, resources, support, decision guide and external sensors   | yes                  | yes                    | yes                | no          | yes          | no   | Caregiver factors, care recipient factors and other factors |
| STAR training portal (Hattink et al., 2015)            | 2 months                   | 8 modules on dementia care; a Learning Path Advisor accessed through an integrated online tool assessed baseline knowledge; Facebook and LinkedIn communities to promote peer support  | yes                  | yes                    | yes                | no          | yes          | 1) the medical model of dementia, and (2) the adaption-coping model of Dröes et al. (2011) | Caregiver factors, care recipient factors                   |
| The electronic intervention (Hicken et al., 2017)      | 4-6 months                 | In English and Dutch, Swedish, Italian, Romanian<br>Available for a nominal fee<br>The electronic intervention (home internet or tele-health) included 1) video, once per week, portraying dementia progression and caregiving skills; 2) written information about health topics and caregiving skills and 3) brief assessments of caregiver health and | yes                  | unclear                | unclear            | yes         | no           | no   | Caregiver factors, care recipient factors                   |
| The iCare program (Kajiyama et al., 2013)              | 3 months                   | 6 modules covering dementia care information delivered in embedded video clips and via a workbook.   | yes                  | yes                    | yes                | no          | no           | no   | Caregiver factors, care recipient factors and other factors |
| RHAPSODY (Metcalfe et al., 2019)                       | 6 weeks, unlimited access  | Available for purchase<br>7 modules covering young onset dementia, information, problems and solutions, care and support, and self-care<br>Written and video content, case-studies, presentations from professionals and downloadable materials. Available in English, French, German, and Portuguese  | yes                  | yes                    | yes                | no          | no           | no   | Caregiver factors, care recipient factors                   |
| UnderAID Nunez-Naveira et al., 2016)                   | 3 months                   | 5 modules with information about 15 different topics, covers information about the care of a PwD and caring for oneself as a caregiver   | yes                  | yes                    | yes                | no          | yes          | no   | Caregiver factors, care recipient factors                   |
| ALADDIN (Torkamani et al., 2014)                       | 6 months                   | Includes 1) dementia information and educational material; 2) social network-discussion forum; 3) my tasks-distance monitoring feature; and 4) contact us links  | yes                  | unclear                | unclear            | no          | yes          | no   | Caregiver factors, care recipient factors and other factors |
| The CARES for Families (Gaugler et al., 2015)          | NI                         | CARES for Families modules included three 1-hour modules covering the following topics: 1) understanding memory loss: seven screens, 17 videos, 2) living with dementia 18 screens, four videos, and (3) using the CARES Approach 11 screens, 18 videos  | yes                  | yes                    | yes                | no          | no           | no   | Caregiver factors, care recipient factors                   |

(Continued)

**Table 2.** Continued.

| Program/Study   | Duration | Content  | Theoretical training | Psychological training | Behaviour training | Facilitator | Peer support | Theoretical framework    | Relations to the SHP model                                  |
|---|----------|--|----------------------|------------------------|--------------------|-------------|--------------|--------------------------|---|
| Caring for Me (Marziali & Garcia, 2011)                       | 6 months | Includes 1) online Dementia Caregiver Information Handbook 2) email link for peer group members; 3) text-based chat forum; 4) video conferencing link for group meetings; and 5) library of educational videos.  | yes                  | yes                    | yes                | yes         | yes          | Stress and coping theory | Caregiver factors, care recipient factors and other factors |
| Education message via telegram channel (Mollaei et al., 2021) | 4 weeks  | 6 educational messages per week and weekly group meeting with researchers  | yes                  | yes                    | yes                | yes         | yes          | no                       | Caregiver factors, care recipient factors and other factors |
| CARES Dementia Basics online program (Pleasant et al., 2017)  | 2 weeks  | 4 modules: 1) Meet Clara Jones, an introduction to person-centred care; 2) introduction to dementia; 3) understanding behaviour as communication; and 4) the CARES® approach to Connect, Assess, Respond, Evaluate, and Share with other team members when providing care  | yes                  | yes                    | yes                | no          | no           | person-centred care      | Caregiver factors, care recipient factors                   |
| DEM-DISC (van der Roest et al., 2010)                         | 2 months | Internet source contains information on diagnosing dementia, practical support, coping, finding company, and service providers in the region.  | yes                  | yes                    | yes                | no          | no           | no                       | Caregiver factors, care recipient factors and other factors |
| Through the D'mentia Lens (Wijma et al., 2018)                | 3 weeks  | 13 min using VR device includes scenes of the person with dementia alone; interaction with informal carer and interaction with a group of people (face to face).<br>online e-course: 20 min lessons x 3, includes problem associated with dementia, communication with PwD, dementia in social life. At home, reflected on what had been experienced in the simulation movie | unclear              | Yes                    | yes                | no          | no           | no                       | Caregiver factors, care recipient factors                   |

Note. Theoretical training: clear scientific and multidisciplinary information about dementia disease; Psychological training: support to improve the caregiver's feelings and reactions towards care recipients; Behaviour training: support to manage behavioural issues (Dumont et al., 2016); SHP = stress and health process; Caregiver factors = contextual factors (i.e. family relationships, co-residing status); care recipient factors = primary stressors (i.e. changed behaviours); other factors = secondary stressors (i.e. family conflict, financial difficulties, social support).



2014). Compared to control groups, internet-based psychoeducational programs had no significant effect on caregiver's QoL [effect size = 0.18; confidence interval (-0.22, 0.58),  $p=0.38$ ] (Supplementary material).

### Caregiver's depressive symptoms

Eight RCTs were included in the meta-analysis of the effectiveness of internet-based psychoeducational programs on caregiver's depressive symptoms (Baruah et al., 2021; Blom et al., 2015; Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Kajiyama et al., 2013; Nunez-Naveira et al., 2016). Compared to control groups, internet-based psychoeducational programs had a significant effect on caregiver's depressive symptoms [effect size = -0.19; confidence interval (-0.35, -0.03),  $p=0.02$ ] (Supplementary material).

Two RCTs had program facilitators and these studies were included in a sub-group analysis (Blom et al., 2015; Boots et al., 2018). Compared to control groups, internet-based psychoeducational programs with a facilitator had a significant effect on caregiver's depressive symptoms [effect size = -0.29; confidence interval (-0.54, -0.03),  $p=0.03$ ] (Supplementary material).

Six RCTs without a facilitator were included in a sub-group analysis (Baruah et al., 2021; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Kajiyama et al., 2013; Nunez-Naveira et al., 2016). The result revealed that internet-based psychoeducational programs without a facilitator had no effect on caregiver's depressive symptoms [effect size = -0.13; confidence interval (-0.33, 0.07),  $p=0.21$ ] (Supplementary material).

### Caregiver's stress

Six RCTs were included in the meta-analysis of the effectiveness of internet-based psychoeducational programs on caregiver's stress (Boots et al., 2018; Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Kajiyama et al., 2013; Metcalfe et al., 2019; Torkamani et al., 2014). Compared to control groups, internet-based psychoeducational programs showed a significant reduction in caregiver's stress [effect size = -0.29; confidence interval (-0.52, -0.06),  $p=0.01$ ] (Supplementary material).

### Caregiver's self-efficacy

Seven RCTs were included in the meta-analysis of the effectiveness of internet-based psychoeducational programs on caregiver's self-efficacy (Baruah et al., 2021; Boots et al., 2018; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Hattink et al., 2015; Metcalfe et al., 2019; Nunez-Naveira et al., 2016). Compared to control groups, internet-based psychoeducational programs had no significant effect on caregiver's self-efficacy [effect size = 0.10; confidence interval (-0.12, 0.33),  $p=0.37$ ] (Supplementary material).

### Caregiver's anxiety

Three RCTs were included in the meta-analysis of the effectiveness of internet-based psychoeducational programs on caregiver's anxiety (Blom et al., 2015; Boots et al., 2018; Gustafson et al., 2019). Compared to control groups, internet-based psychoeducational programs showed no significant effect on caregiver's anxiety [effect size = -0.12; confidence interval (-0.76, 0.51),  $p=0.71$ ] (Supplementary material).

### Caregiver's burden

Six RCTs were included in meta-analysis of the effectiveness of internet-based psychoeducational programs on caregiver's burden (Baruah et al., 2021; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Hattink et al., 2015; Metcalfe et al., 2019; Torkamani et al., 2014). Compared to control groups, internet-based psychoeducational programs showed no significant effect on caregiver burden [effect size = -0.03; confidence interval (-0.26, 0.20),  $p=0.82$ ] (Supplementary material). A summary of meta-analysis findings is provided in Supplementary material Appendix E.

### Description of studies not included in meta-analysis

Two RCTs did not have sufficient available data to be included in the meta-analysis despite us contacting authors (Duggleby et al., 2018; Hicken et al., 2017). Data from six pre-and post-test studies were not suitable for inclusion in the meta-analysis, but study results showed these programs to significantly improve participants' mental health (Marziali & Garcia, 2011), well-being (Mollaei et al., 2021), knowledge of dementia (Gaugler et al., 2015; Pleasant et al., 2017) and competence (Pleasant et al., 2017; van der Roest et al., 2010; Wijma et al., 2018). Within these studies, there was no change in caregiver burden, QoL or self-efficacy (Duggleby et al., 2018; Hicken et al., 2017; van der Roest et al., 2010).

### Discussion

Our meta-analyses showed internet-based psychoeducation programs have a significant effect on caregiver's depressive symptoms and stress, but have no statistically significant effect on caregivers' QoL, burden and self-efficacy. We developed a clear definition of internet-based psychoeducational programs and used it in the selection of studies which allows future studies or reviews to compare the outcomes. Furthermore, the use of the 'stress and health process' model informed program analysis and outcome measures of internet-based psychoeducation interventions (Conde-Sala et al., 2010). These measures were based on the theoretical assumption that psychoeducation programs address multifaceted factors including caregiver contextual factors (caregiver factors), primary stressors (care recipient factors) and secondary stressors (other factors) by which they have a positive effect on the health, wellbeing and QoL of caregivers (Conde-Sala et al., 2010). Previous systematic reviews on the impact of psychoeducation interventions rarely detailed relations between the program content and the multifaceted factors the content addressed (Egan et al., 2018; Gonzalez-Fraile et al., 2021).

We carefully analysed the content of each psychoeducation program included in the review and clarified the relations between the program content and the aforementioned multifaceted factors (see Table 2). Program content that addressed caregiver factors included positive thoughts towards the relationship with PwD due to dementia (Blom et al., 2015; Boots et al., 2018); and how to be a caregiver (either as an adult-child caregiver or a spouse caregiver) (Baruah et al., 2021). Moreover, content that helped caregivers to cope with care recipient factors comprised how to prevent and manage changed behaviours (Hattink et al., 2015; Metcalfe et al., 2019), and how to provide activities of daily living to address the functional deficits of PwD (Cristancho-Lacroix et al., 2015; Nunez-Naveira et al., 2016). In

addition, content that enabled caregivers to deal with other factors included how to seek help within and outside the family (i.e. peer support and support from facilitators (Gustafson et al., 2019; Kajiyama et al., 2013)). This theory-informed analysis may enhance confidence for stakeholders to translate findings into practice.

Our meta-analyses showed that internet-based psychoeducational programs had a significant effect on the reduction of depressive symptoms. The depression reduction identified in our review showed the same effect size (-0.19) to psychoeducation-a programs, but a smaller effect size compared to psychoeducation-b programs (effect size = -0.37), as that reported by Cheng et al. (2020) in their review. It should be noted that of the eight studies included in our meta-analysis of depressive symptoms, only one study was a psychoeducation-a program according to the definition by Cheng et al. (2020). Therefore, our result may indicate that internet-based psychoeducation programs are less effective in depression reduction compared to psychoeducation-b programs (Cheng et al. 2020). It also should be mentioned that the systematic review and meta-analysis by Cheng et al. (2020) included an additional 46 psychoeducation programs excluded from our review according to our definition of psychoeducation programs. Excluded programs had a broader range of program delivery methods than our focus here such as face-to-face and telephone-based programs and other information technology formats (i.e. video conferencing, web platforms or DVD based self-learning programs) and may or may not have facilitators (Cheng et al., 2020). Therefore, reported differences in effectiveness of psychoeducation programs between our review and the review by Cheng et al. (2020) may be due to program delivery methods. Future studies need to explore the impact of program delivery on the program effectiveness.

Our sub-group analysis indicated that programs with a facilitator had a significant effect on reducing depressive symptoms (Figure 3.3), while programs without a facilitator showed no significant effect (Figure 3.4). Of the 19 programs reviewed, nine had program facilitators, and two of these studies were included in this sub-analysis. The role of facilitators in these two programs were similar and included a trained psychologist who provided feedback to caregivers (Blom et al., 2015; Boots et al., 2018). Our review supports a previous review that increased professional support in a dementia care education program were associated with a better effect on caregiver depressive symptoms (Zhao et al., 2019). The mechanism underlying the better effect might be due to the facilitator's role as a mediator to address caregiver contextual factors and care recipients' factors (Huang, 2022). However, as we only included two studies in the meta-analysis, the result needs to be interpreted with caution and future studies need to further explore the relationships.

Our meta-analysis also revealed that internet-based psychoeducational programs had a significant effect on improving caregivers' emotional wellbeing as evidenced by stress reduction. The effect size of internet-based psychoeducational programs (-0.29 on stress) is similar to that reported by Cheng et al. (2020) (effect size = -0.23 on stress and burden). This is evidence that internet-based psychoeducational programs show similar reduction of stress compared to psychoeducation programs delivered by various other methods as aforementioned.

Our findings suggested that internet-based psychoeducation programs did not have a significant effect on reducing anxiety symptoms. This may be due to the risk factors underlying anxiety differing from depression. Watson et al. (2019)

suggested that anxiety symptoms were associated with female gender, spousal caregivers, care recipients' condition, low levels of self-efficacy and other existing underlying anxiety problems. In our systematic review, the majority of participants in the three studies that measured anxiety included in the meta-analysis were female spouse carers living with PwD in the same household. These characteristics are related to caregiver contextual factors based on the 'stress and health process' model (Conde-Sala et al., 2010). Addressing these factors may require instrumental support such as social care services (i.e. respite care and home care services for PwD) (Brodaty & Donkin, 2009). Our review suggested that an internet-based psychoeducation program alone may not be sufficient to achieve anxiety reduction. Future studies need to explore interventions that include multiple approaches such as emotional and instrumental support, counselling and peer support groups for reducing anxiety among caregivers.

The present review suggests that online psychoeducation programs have no statistically significant effect on caregiver burden. Research showed that caregiver burden were associated with PwD's high level of dependence (primary stressors) and less social support for caregivers (Connors et al., 2020). In this review, we were unable to clarify the correlation between caregiver burden and primary stressors and between caregiver burden and social support they received due to limited data available. However, a systematic review and meta-analysis by Williams et al. (2019) revealed that only multiple approaches, for example respite care, home care for PwD, peer support groups and psychoeducation, showed significant burden reduction.

Our review showed that internet-based psychoeducational programs did not have a significant effect on caregiver self-efficacy. Our finding differs from a systematic review that showed a significant effect on self-efficacy in group-based face-to-face psychoeducational programs (Frias, Garcia-Pascual, et al., 2020). The differences may be due to the learning environment for caregivers. In group-based face-to-face programs, caregivers had opportunities to interact with peers to share experiences in dementia care, learn from and be motivated by role models, gain emotional and social support, and gain information to cope with challenges (Frias, Garcia-Pascual, et al., 2020). This environment reflects Bandura's self-efficacy development theory that emphasises a person's ability to learn a particular task and the environmental factors which influence the learner through cognitive, motivational, affective and behavioural processes (Bandura, 1993).

Our review also revealed that internet-based psychoeducational programs did not have a statistically significant effect on QoL. The finding is in line with a systematic review by Frias, Garcia-Pascual, et al. (2020) who reported that technology-based intervention (i.e. Website and telephone assisted interventions) had no significant effect on QoL. However, findings from Frias, Garcia-Pascual, et al. (2020) were based on narrative summary, rather than a meta-analysis and our review did not include telephone assisted interventions. Moreover, Frias, Garcia-Pascual, et al. (2020) stated that face-to-face group interventions showed significant improvement on QoL. This result may be due to multiple approaches to interventions being included in group-based face-to-face psychoeducational programs than internet-based programs; for example, offering additional individualised supports such as providing resources, information, follow-up phone calls and help with navigating the health and social care system (Frias, Garcia-Pascual, et al.,

2020). However, among six studies that measured QoL in our review, five programs were self-directed learning which means no additional support to caregivers in the Internet-based psychoeducation programs (Baruah et al., 2021; Hattink et al., 2015; Kajiyama et al., 2013; Metcalfe et al., 2019; Torkamani et al., 2014). Moreover, the comparison groups in the six studies on QoL in our review received usual care ( $n=3$ ) (Hattink et al., 2015; Metcalfe et al., 2019; Torkamani et al., 2014), additional information support ( $n=2$ ) (Baruah et al., 2021; Kajiyama et al., 2013) and infrequent counselling (Boots et al., 2018), which were similar to the comparison groups in the review of face-to-face programs ( $n=5$ ) by Frias, Garcia-Pascual, et al. (2020) which included usual care ( $n=4$ ) and additional information support ( $n=1$ ). Therefore, the differences on QoL might not be associate with the comparison groups, but the multiple approaches to interventions used in the face-to-face programs aforementioned. Future interventional programs need to consider multiple approaches to interventions in order to improve QoL for caregivers.

Crellin et al. (2014) in their systematic review identified that dementia caregiving related self-efficacy was a main factor contributing to caregivers' QoL. In addition, Farina et al. (2017) in their systematic review confirmed at least 10 factors associated with caregivers' QoL, for example care recipient factors, didactic relationship factors, caregivers' self-efficacy, health and emotional wellbeing, and support received. These findings suggest that future internet-based psychoeducational programs should be designed to target as many QoL factors as possible to achieve a positive effect for caregivers.

### Strengths and limitations

This review had several strengths. First, the literature search covered both English and Chinese language databases which reduced bias. Second, we performed a meta-analysis to calculate the effect size of changed mean score which is crucial for comparisons between internet-based and the non-internet-based psychoeducational programs. In addition, we included pre- and post-test studies in addition to RCTs to analyse the educational designs. There were also several limitations of this review. First, while this review searched English and Chinese language literature, it could have expanded to other languages if other multilingual researchers were included in the study team. Second, variations in program design, intervention duration, dose and socio-cultural contexts prevented us from undertaking sub-group analysis to calculate precise intervention effect size.

### Conclusion

Internet-based psychoeducation programs showed increased importance during the covid-19 pandemic due to restrictions on social contacts and the interruption of face-to-face education programs for caregivers. Our review indicated that internet-based psychoeducational programs show a significant effect on depressive symptoms and stress reduction. However, our findings also indicate that internet-based psychoeducational programs have no effect on reducing anxiety, burden, and improving self-efficacy or QoL for caregivers. Future studies need to explore how to improve internet-based psychoeducational programs to maximise effectiveness and the impact of program facilitators on the health and wellbeing of caregivers.

### Authorship statement

All authors listed meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors and all authors agree with the manuscript.

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No potential conflict of interest was reported by the authors.

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