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Review

eHealth interventions for family carers of people with long term illness: A promising approach?

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HIGHLIGHTS

- 78 studies reporting 62 interventions were identified across illness conditions.
- Dementia is the most researched area, as reported in 40% of studies.
- Study designs and quality vary widely; usability studies are unique to the field.
- Psychoeducation, with or without network support, is the most common approach.
- eHealth interventions are desirable due to flexibility in access, content and use.

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ABSTRACT

Family carers of people who have long term illness often experience physical and mental health morbidities, and burden. While there is good evidence to suggest that carers benefit from psychosocial interventions, these have primarily been delivered via face-to-face individual or group-formats. eHealth interventions offer a novel, accessible and self-paced approach to care delivery. Whether these are effective for carers' wellbeing has been little explored. This paper reports the first comprehensive systematic review in this area. A total of 78 studies, describing 62 discrete interventions, were identified. Interventions commonly aimed to promote carers' knowledge, self-efficacy, caregiving appraisal, and reduce global health morbidities. Interventions were offered to carers of people with a wide range of long term illness; dementia has been the most researched area, as reported in 40% of studies. Clinical and methodological heterogeneity in interventions precluded meta-analyses, and so data were analysed narratively. The most popular approach has comprised psychoeducational interventions delivered via an enriched online environment with supplementary modes of communication, such as network support with professionals and peers. Overall, carers appreciate the flexibility and self-paced nature of eHealth interventions, with high rates of satisfaction and acceptability. More studies using robust designs are needed to extend the evidence base.

1. Introduction

Worldwide, a significant proportion of people provide substantial and sustained help and support to friends or family members suffering from a long term illness (Shahly et al., 2013). In the UK, the 2011 Census found that 10% of the population in England and Wales self-identifies as a carer or care-giver (White, 2013). The 2007 Adult Psychiatric Morbidity Survey (APMS) reported that 25% of 1883 participants were carers (Smith et al., 2014). According to the US National Alliance for Caregiving (a nation-wide charity, 2009), up to 29% of

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adults are a carer for a relative who is ill, disabled or elderly. Informal or family caregiving can be a fulfilling experience and enrich relationships. Moreover, carers' unpaid input is of substantial economic value to society as a whole (Carers Trust, 2014; National Alliance for Caregiving, 2009; Shahly et al., 2013). Importantly, however, it is well-established that the burden of caring can adversely affect carers themselves, including incurring clinically significant physical and psychological morbidities, and financial and social challenges (Carers Trust, 2014; National Alliance for Caregiving, 2009). Of note, there is a direct relationship between the physical and mental health of carers, and the amount of care they provide: as the amount of care increases, the health of carers worsens (Smith et al., 2014). Furthermore, the wellbeing of carers is associated with their caregiving capacity, that is, poorer wellbeing affects propensity to provide adequate support (Cooper, Blanchard, Selwood, Walker, & Livingston, 2010; Sin, Murrells, Spain, Norman, & Henderson, 2016). This demonstrates that the health outcomes of carers and cared-for people are often inter-related.

Consequently, interventions for carers (with or without cared-for individuals) have been developed for a range of long term physical and mental illness, in particular dementia. Interventions such as psychoeducation (e.g. Sin et al., 2017; Sin, Gillard, et al., 2016; Sin & Norman, 2013; Yesufu-Udechuku et al., 2015), mutual/peer support programmes (e.g. Burnell et al., 2012; Chien et al., 2011) and coping strategies/self-management packages (e.g. Gallagher-Thompson et al., 2002; Livingston et al., 2014), delivered through conventional face-to-face mediums, have been found to be effective in enhancing carers' knowledge and their capacity to cope. In turn, this can positively impact on patients' outcomes. However, carers consistently describe difficulties with accessing these interventions in routine health and social care services (Carers Trust, 2014; National Alliance for Caregiving, 2009); in part, due to a lack of funding or resources, unmet training needs of the workforce, and service priorities which are centred on patients (Sin et al., 2017; Sin, Gillard, et al., 2016; Sin, Henderson, Spain, Gamble, et al., 2016). Moreover, carers often report that they would like interventions to be offered and delivered via flexible and self-paced packages, ideally via online mediums, which can be managed around their commitments (Powell & Clarke, 2006; Powell et al., 2013; Powell, Jennings, Armstrong, Sturt, & Dale, 2009; Sin, Moone, Harris, Scully, & Wellman, 2012).

eHealth (or e-health) interventions are defined as healthcare practice delivered via the internet (Eysenbach, 2001; Vincenzo, 2001): these seem to offer a solution. During the last decade, in line with the increasing popularity and availability of information and communication technology (ICT), eHealth interventions for carers have been rapidly emerging (Eysenbach, 2001; Riper et al., 2010). eHealth interventions have included psychoeducation, coping strategies/self-management and social support, as well as remote monitoring, consultation (including decision support aid), psychosocial therapies and clinical care (Chi & Demiris, 2015; Powell et al., 2008).

To date, most eHealth and mHealth (or m-health, using mobile technologies such as smart phones or wearable devices) studies have focused on patients' health outcomes and/or clinicians' perspectives (Powell et al., 2008; Riper et al., 2010). Few studies have investigated eHealth or mHealth interventions for family carers. One previous review has focussed on telehealth interventions including those delivered via for example phone calls (including land-line phones) and CD-ROM (Chi & Demiris, 2015). However, these specific interventions do not meet the criteria for eHealth interventions (i.e. not delivered through the internet) (Cantoni & Danowski, 2015; Vincenzo, 2001), nor do they include any interactions between intervention providers/therapists and the recipients or obtain data from participants. In contrast, eHealth and mHealth interventions can facilitate interactions between all parties as well as record usage and outcome data (such as number of log-ins, time spent, and content accessed) through the internet medium. These communication and automatic data collection and storage features can enhance engagement in an efficient manner (Eysenbach, 2001; Vincenzo, 2001).

We aimed to conduct a comprehensive systematic review about eHealth and mHealth interventions for family carers of people with a long term illness. Specifically, we sought to investigate all interventions delivered partially or completely using ICT, designed to promote carers' wellbeing or factors related to health morbidity (e.g. knowledge or burden). Specific objectives included: (1) to scope the designs and carer outcome measures used in studies; (2) to outline the common intervention content, design and ICT features including, where reported, any theoretical underpinning to the intervention; and (3) to describe carers' experiences and perceived acceptability of interventions. Further, (4) we examined controlled studies that assessed effectiveness/efficacy (see inclusion criteria below) to consider the possible effects of such interventions in promoting carers' outcomes. We sought data that would identify potential intervention and population moderating factors and implementation/facilitation considerations of intervention effectiveness/efficacy.

2. Methods

We published the review protocol in PROSPERO (International Prospective Register of Systematic Review) (Sin, Henderson, Spain, Cornelius, et al., 2016). The review process followed PRISMA guideline (Moher, Liberati, Tetzlaff, Altman, & Group, 2009).

2.1. Data sources and search strategy

Searches for papers written in either English or Chinese languages (given the available resources within the review team), from January 1999 to December 2016, were conducted using: Medline; PsycInfo; CINAHL; Embase; Web of Science; ASSIA; Cochrane Central Register of Controlled Trials (CENTRAL); NIHR-Health Technology Assessment (HTA) database; Database of Abstracts of Reviews of Effect (DARE); and NHS Economic Evaluation Database (EED). Year 1999 was the time when eHealth interventions were first documented (Eysenbach, 2001; Vincenzo, 2001). In addition, the reference lists of all included studies were checked. Authors of included articles were contacted to retrieve relevant information about their study that was either not reported or unclear from the article.

We devised the search terms using the PICO approach (River, Malik, Burnie, Endicott, & Busse, 2012) (see Supplementary Table 1). As the search aimed to be highly sensitive, we employed an initial search strategy combining search terms for population (e.g. family/informal/unpaid carer*, partner*/spouse*, parent*/father*/mother*, siblings) and interventions (e.g. online/web/internet/digital, [e* OR mobile] adj3 [psychoeducation* OR health education OR counselling OR cognitive behaviour* therapy OR self-manage* OR help* OR peer or mutual [adj1] support]).

2.2. Study selection

We included carers with no lower or upper age limit as long as individuals had an emotional bond with the cared-for person for whom they provided unpaid care. We included extended family members or relatives and close friends who fulfilled all inclusion criteria but did not necessarily have a biological relationship with or live with the patient. We adopted a pragmatic definition of long term illness that included both mental and physical illness that is either progressive or relapsing in nature, and persisting for six months or longer, to an extent that impeded patient's functioning and thus requires significant amount of care (Burnell et al., 2012). We excluded studies in which patients resided in a care setting and thus, most care was provided by paid staff (such as hospitals, residential care homes, and hospices).

We included any ICT interventions, which may have been supplemented with other modes of treatment, such as face-to-face sessions.

Carers could either be the sole recipient of interventions, or as a matched pair with their cared-for person. Intervention content could include: information; emotional support (e.g. peer-to-peer support); management or coping with caring; appraisal of caring experience (e.g. cognitive or cognitive behavioural treatment); virtual applications; games; and/or a combination of these features. Interventions facilitated by qualified health- or social care personnel and/or lay persons with or without experiential knowledge of caring (e.g. carer-peers or volunteers) were included. However, we excluded interventions solely designed to monitor or improve carers' practical skills (e.g. safe handling for bathing a relative, or taking their blood pressure) or limited to the provision of financial and day-to-day practical support (e.g. personal assistance or carer benefits/payments). In order to describe the state of the field comprehensively, we included empirical studies using any designs and with carer outcomes reported using specified quantitative or qualitative measures/tools (validated or not).

Two authors (JS and DS) independently screened initial records identified, and full text articles of shortlisted papers based on titles and then abstracts. A proportion of searches, screening and study selection was reviewed by other authors (CH and SG) at various stages. Disagreements were resolved through: (1) seeking additional data or clarification from study authors when possible; and (2) review team discussion.

2.3. Data extraction and analysis

Relevant extracted data were entered into the included studies summary table. We extracted study design and data variables from each included study for further analysis, including: study design; sample size; setting; carer characteristics (such as age, gender, relationship with patients); diagnosis of patients; carer (and any other) outcome measures; time-points; control condition or comparator, if applicable. We also extracted data pertaining to intervention design: intervention aim (s); theoretical framework if used and described; content and features; duration of intervention both in terms of usage hours if specified and the period during which the intervention was undertaken.

In addition, we scoped the modes of delivery used by the identified interventions for carers, by adopting a coding system for online behavioural change interventions devised by Webb and colleagues (Webb, Joseph, Yardley, & Michie, 2010). According to the scheme, modes of delivery were divided into three categories: (1) automated functions; (2) communicative functions; and (3) use of supplementary modes. Each category includes a list of delivery modes, as listed below. We noted whether or not each intervention used any of these modes.

(1) Automated functions included: (a) the use of an enriched information environment (e.g. supplementary content and links, testimonials, videos, or games); (b) automated tailored feedback based on individual progress monitoring (e.g. comparison to norms or goals, reinforcing messages, or coping messages); and (c) automated follow-up messages (e.g. reminders, tops, newsletters, encouragement).
(2) Communicative functions included: (d) access to an advisor to request advice (e.g. “Ask the expert” facility; expert-led discussion board; or chat sessions); (e) scheduled contact with advisor (e.g. emails); (f) peer-to-peer access (e.g. buddy systems, peer-to-peer discussions boards; forums; or live chat).
(3) Use of supplementary modes included the use of: (g) email; (h) phone (changed from telephone) including Short Messaging Service (SMS); (i) skype (changed from CD-ROM); (j) videoconferencing; or (k) avatar. We had adapted items (h) and (i) and added item (k) to reflect the evolution of technologies (Webb et al., 2010).

Interventions were further categorised according to their delivery mode(s) and overall approach as: online/mobile therapy (e.g. psychoeducation or CBT); online/mobile social networking (e.g. carer forum); combined therapy and networking; other online/mobile resources (e.g. guideline, advocacy); or eHealth/mHealth augmenting face to face treatment. This category system was adapted from previous literature focusing on patient-centred interventions, which has found that the user group, delivery format and social networking are likely to influence intervention take-up and effectiveness (Alvarez-Jimenez et al., 2014; Chi & Demiris, 2015; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004).

Data analysis started with an overview of study and intervention characteristics followed by tabulation of extracted data. Due to the heterogeneous nature of the data across clinical, methodological and intervention domains, a narrative approach was used to synthesise the data. Thematic synthesis was undertaken to address each review objective.

2.4. Assessment of study quality

Given the wide variety of study designs, we employed the integrated criteria for review of multiple study designs (ICROMS by Zingg et al., 2015) to assess quality. The tool consists of two parts: (1) a list of quality criteria specific for each study design (such as RCTs, qualitative studies, and cohort studies), as well as criteria applicable across all study designs by using a scoring system; and (2) a ‘decision matrix’, which specifies the robustness of the study by identifying minimum requirements according to the study type and the relevance of the study to the review questions. All studies, regardless of design used, were assessed for seven dimensions: clear aims and justification; managing bias in sampling or between groups; managing bias in outcome measurements and blinding; managing bias in follow-up; managing bias in other study aspects; analytical rigour; and managing bias in reporting/ethical considerations. Each criterion was evaluated on a three-point scale (2 = criterion met; 1 = unclear; 0 = criterion not met). For study designs that did not have a specific ICROMS quality criteria (Zingg et al., 2015), such as studies using survey questionnaires and mixed qualitative and quantitative methods, we rated these using the qualitative studies criteria as the most appropriate choice. For trials evaluating devices or interventions specifically, we also used the CONSORT-eHealth Checklist (v.1.6.1) (Eysenbach & CONSORT-EHEALTH Group, 2011) to assess the trial reporting quality.

Each article was independently assessed by two of the three co-authors (JS, DS or SG) and discrepancies were resolved by seeking further opinion and consensus from other authors. One included study was written by co-authors of this review (Sin, Henderson, & Norman, 2014); none of the authors were involved in the quality assessment of their own paper.

3. Results

The search retrieved 7016 records initially. After a stepwise process of screening titles, abstracts and then full-text papers against our eligibility criteria, we read 182 full text papers at the final screening stage. Of these we included 81 papers describing 78 studies, and which reported on 62 discrete interventions. All included papers were published in English. One eHealth intervention targeting the carers of individuals with eating disorders was tested in two separate RCTs, with the original trial conducted in the UK (Grover et al., 2011) and another in Australia with additional online clinician support (Hoyle, Slater, Williams, Schmidt, & Wade, 2013). One study reported carers' qualitative and quantitative outcomes in two papers separately (Swallow et al., 2016; Swallow, Webb, & Smith, 2015). Two further intervention trials were reported in two papers with different follow-up time-points (Rotondi et al., 2010; Rotondi, Haas, et al., 2005) and different outcomes (Piette, Striplin, Marinec, Chen, & Aikens, 2015; Piette et al., 2015) respectively. Furthermore, ten interventions were reported by multiple studies along its development, feasibility/usability testing and effectiveness evaluation. An example was a French study about an eHealth

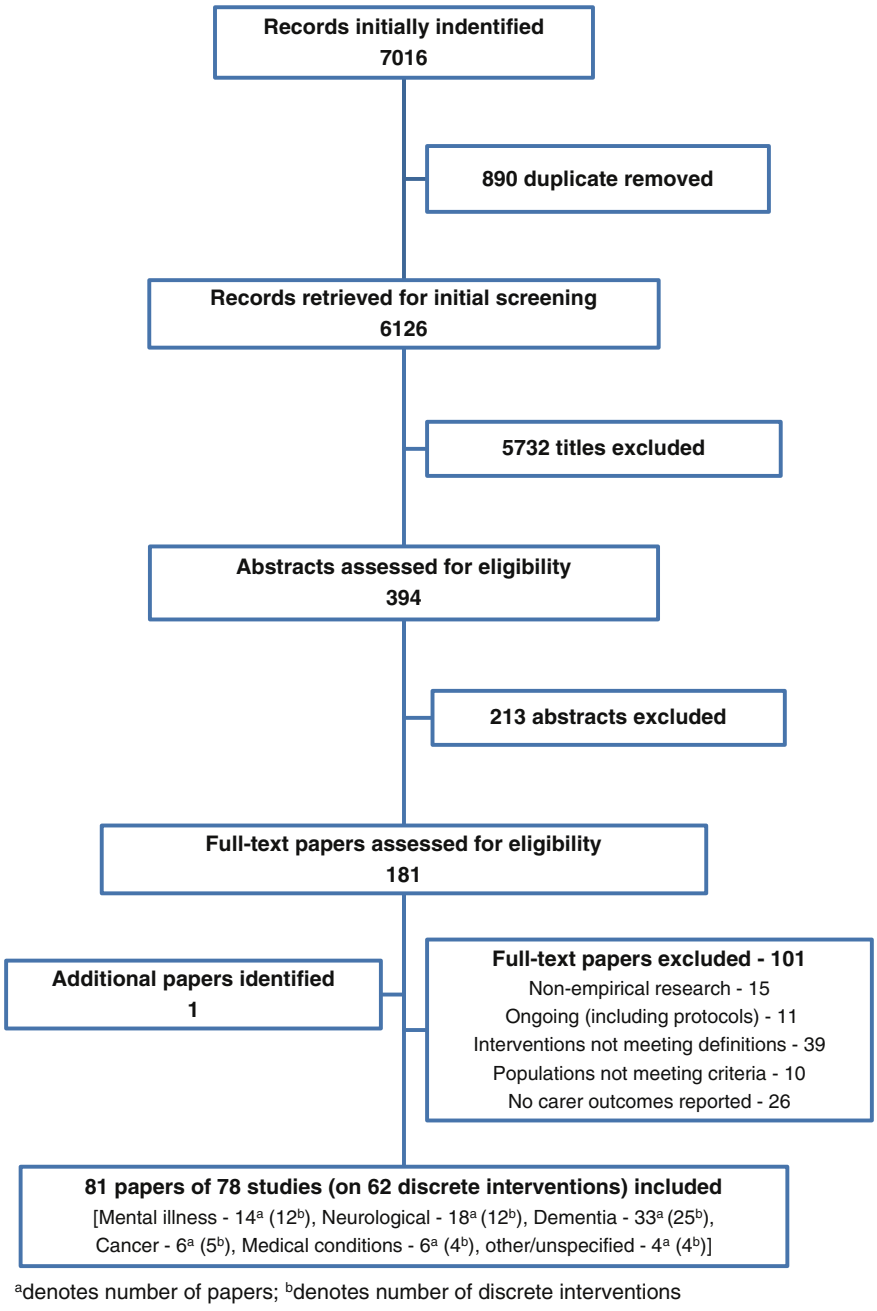

Fig. 1. PRISMA diagram.

intervention for dementia carers: one paper described the intervention development process and its usability testing (Cristancho-Lacroix et al., 2014); another paper reported on its effectiveness on carers' outcomes through a RCT(Cristancho-Lacroix et al., 2015). Apart from two studies investigating two discrete interventions which were unpublished doctoral theses (Candell, 2003; Zimmerman, 2014), all other included papers were published, mostly in scientific journals. The search process and results are presented in Fig. 1; and the included studies summarised in Table 1 (in reporting the results below, studies are referred to according to the numbering in Table 1).

3.1. Overview of included studies

Overall, the included papers covered 4537 carers and 1077 patients, as 11 out of 78 (14%) studies recruited both patients and carers and reported their respective outcomes. Most of the studies were conducted in North America: 43 in U.S.A. and seven in Canada. Europe hosted 22 studies, five of which were based in U.K. Six remaining studies originated in the Pan-Asia region: three in Australia and three in Hong Kong, China. We grouped studies according to illness conditions: mental illness (studies 1–13); neurological conditions such as traumatic brain injury (TBI) (studies 14–31); dementia (studies 32–64); cancer (studies 65–70); medical conditions, such as heart failure and cystic fibrosis (studies 71–74); and general disability and unspecified long term illness (studies 75–78). Nine studies specifically targeted parent-carers for paediatric or adolescent patients suffering a LTI: six on LTI such as TBI and chronic kidney disease (studies 14, 22, 30, 65, 71 & 74) and three on mental illness such as eating disorders and autism spectrum disorders (studies 2, 4 & 13). One study focused on adolescents supporting a parent with severe mental illness (study 12). Studies targeting carers supporting a loved one affected by dementia mostly did not specify the relationships between the carer and the cared-for individual as an

Table 1
Summary of included studies.

Study no.	Study author(s) & year published	Country	Target LTI	Intervention approach	Study design	Comparison (if used)	Carer sample size (PS)	Primary outcome	Outcome measure
Studies on mental illness (1 − 13)									
1	Berk et al., 2013	Australia	Bipolar disorder	Guideline	Post-use survey	N/A	121	Acceptability & usability	Questionnaire
2	Binford Hopf et al., 2013	USA	Eating disorder	Peer groups adjunct with family therapy	Post-use evaluation	N/A	13	Satisfaction, caregiving experience	Questionnaire, ECI
3	Chan et al., 2016	Hong Kong	Psychosis	Online psychoeducation with peer forum	Usability evaluation	N/A	81	Usefulness, ease of use	Questionnaire
4	Clifford and Minnes, 2013	Canada	ASD	Network support	Comparison study	No treatment	45	Depression, anxiety, coping	STDS, STAI, FSCI
5	Grover et al., 2011	UK	Eating disorder	CBT "OAO"	RCT	TAU	63	Depression, anxiety, caregiving experience	HAD, ECI
6	Hoyle et al., 2013	Australia	Eating disorder	Same as study 5 + clinician guidance	RCT	'OAO' only	37	Expressed emotion, distress	EE scale, GHQ-28
7	Ibanga, 2010	UK	Alcohol or drug misuse	5-step method therapy	Development & feasibility study	N/A	67	Feedback, perceived impact	Interview, FMI, CQ, SRT
8	Perron, 2002	USA	Mental illness	Self-help network	Discourse analysis	N/A	33	Post- content & nature	Analysis on posts
9	Rotondi, Haas, et al., 2005*; 2010	USA	Schizophrenia	Psychoeducation with peer forum	RCT	TAU	21 (30)	Distress, social support	RDRD, SSRS, WEI
10	Sin et al., 2014	UK	Psychosis	Psychoeducation with peer forum	Usability study	N/A	20	Usability, usefulness, acceptability	Questionnaire
11	Stjernsward and Ostman, 2011	Sweden	Depression	Network support	Usability study	N/A	20	Usability, acceptability	Focus groups, usability scale
12	Trondsen and Tjora, 2014	Norway	Mental illness	Network support	Qualitative study	N/A	13	Acceptability	Interview
13	Zimmerman, 2014	USA	Autism spectrum disorder	Therapy with peer forum	Pre-post evaluation	N/A	12	Stress, knowledge, acceptability	SIPA, questionnaire
Studies on neurological conditions (14–31)									
14	Antonini et al., 2012	USA	Traumatic brain injury	Psychoeducation	Pre-post evaluation	N/A	20	Feasibility, satisfaction	Interview, questionnaire
15	Candell, 2003	USA	Neurodegenerative diseases	Journaling exercise	RCT	Writing about neutral stimuli	124	Distress	DSC-10R
16	Damianakis et al., 2016	USA	TBI	Same as study 20	Qualitative study	N/A	10	Perceived benefits, group process	Qualitative directed content analysis
17	Lorig et al., 2012	USA	Cognitive impairment	Skill-workshops with peer forum	Pre-post evaluation	N/A	68	Burden, depression	ZBI, PHQ-9
18	Lucas, 2011	USA	Brain tumour	Network support	Evaluation study	N/A	33	Usage, feedback	Usage data
19	Marziali et al., 2005	USA	Neurodegenerative diseases	Same as study 20	Qualitative study	N7/A	34	Satisfaction, usefulness	Interview
20	Marziali and Donahue, 2006	Canada	Neurodegenerative diseases	Therapy group with peer forum	RCT	N/A	66	Feedback, usability	Interview, usage data analysis
21	McLaughlin et al., 2013	USA	Traumatic brain injury	Legislative advocacy training	RCT	Legislative information	201	Advocacy skills application, knowledge, attitudes	Video simulation test, questionnaire
22	Petranovich et al., 2015	USA	Traumatic brain injury	Problem-solving intervention	RCT	Internet resource	132	Distress, depression	SCL-90, CES-D
23	Pierce et al., 2009	USA	Stroke	Psychoeducation with peer forum	RCT	TAU	103 (103)	Depression, life satisfaction	CES-D, SWLS
24	Pierce and Steiner, 2013	USA	Stroke	Same as study 23	Pilot evaluation	N/A	36	Usage, satisfaction	Usage data, questionnaire
25	Pierce et al., 2004	USA	Stroke	Same as study 23	Feasibility study	N/A	9	Acceptability, usage	Phone-interview
26	Pierce et al., 2002	USA	Stroke	Same as study 23	Usability study	N/A	5	Usability, usage	Usage data
27	Rotondi, Sinkule, et al., 2005	USA	Traumatic brain injury	Psychoeducation with peer forum	Feasibility study	N/A	17	Usage, satisfaction	Questionnaire
28	Sander et al., 2009	USA	Traumatic brain injury	Psychoeducation	Post-use survey	N/A	15	Satisfaction, burden	Questionnaire, MCAS
29	Smith et al., 2012	USA	Stroke	Psychoeducation with peer forum	RCT	Information on resource only	38 (38)	Depression, social support	CES-D, SSS-11

(*continued on next page*)

Table 1 (*continued*)

Study no.	Study author(s) & year published	Country	Target LTI	Intervention approach	Study design	Comparison (if used)	Carer sample size (PS)	Primary outcome	Outcome measure
30	Wade et al., 2012	USA	TBI	Problem-solving therapy	RCT	Information on resource only	40	Problem-solving skills, depression	SPSI-R:S, CES-D
31	Wade et al., 2008	USA	TBI	Same as Wade 2012	Feasibility study	N/A	9	Usage, satisfaction	Interview, questionnaire
Studies on dementia (32–64)									
32	Austrom et al., 2015	USA	Dementia	Psychoeducation with peer support	Pre-post evaluation	N/A	5	Anxiety, depression	GAD-7, PHQ-9
33	Blom et al., 2015	Netherlands	Dementia	Psychoeducation	RCT	e-bulletins	245	Depression, anxiety	CES-D, HADS
34	Blusi et al., 2014	Sweden	Dementia	Psychoeducation with peer support	Non-randomized comparison	TAU	95	Preparedness, enrichment, predictability	CES
35	Blusi et al., 2013	Sweden	Dementia	Same as study 34	Qualitative study	N/A	[31 carer from study 34]	Satisfaction	Interview
36	Boots et al., 2016	Netherlands	Dementia	Coaching with peer forum	Pre-post evaluation	N/A	17	Usage, self-efficacy, goal attainment	Usage data, CSES, GAS
37	Chiu et al., 2009	Canada	Alzheimer's disease	Psychoeducation with peer support	Pre-post evaluation	N/A	35	Burden, depression	BSFC, CES-D
38	Chiu and Eysenbach, 2010	Canada	Alzheimer's disease	Same as study 37	Usability study	N/A	[same sample from study 37]	Usage, attrition	Usage data
39	Chiu and Eysenbach, 2011	Canada	Alzheimer's disease	Same as study 37	Secondary qualitative data analysis	N/A	[same sample from study 37]	Factors affecting usage	Usage data, carer characteristics
40	Cristancho-Lacroix et al., 2015	France	Alzheimer's disease	Psychoeducation	RCT	TAU	49	Stress, self-efficacy, burden	PSS-14, RSCSE, ZBI
41	Cristancho-Lacroix et al., 2014	France	Alzheimer's disease	Same as study 40	Prototype test	N/A	6 (43)	Ease of use, feedback	Observation, questionnaire
42	Czaja and Rubert, 2002	USA	Alzheimer's disease	Same as study 43	Usability test	N/A	76	Ease of use	questionnaire
43	Eisdorfer et al., 2003	USA	Alzheimer's disease	Augmented family therapy	RCT	Minimal support or family therapy only	225	Depression, Burden	CES-D, RMBPC
44	Finkel et al., 2007	USA	Alzheimer's disease	Psychoeducation with peer support	RCT	Basic information materials	46	Depression, Burden	CES-D, RMBPC
45	Fowler et al., 2016	USA	Dementia	Psychoeducation with peer forum	RCT	Sleep-actigraphy band only	28	Self-efficacy, insomnia severity, sleep quality & quantity	CSES, ISI, sleep actigraphy band
46	Glueckauf et al., 2004	USA	Alzheimer's disease	Psychoeducation with peer support	Pre-post evaluation	N/A	40	Self-efficacy, emotional growth, appraisal	CSES, SGS, CAI
47	Glueckauf and Loomis, 2003	USA	Alzheimer's disease	Same as study 46	Prototype test	N/A	20	Clarity, usefulness, ease of use, helpfulness	Questionnaire
48	Griffiths et al., 2016	USA	Dementia	Psychoeducation with peer forum	Pilot evaluation	N/A	30	Burden, depression, anxiety, competence	ZBI, CES-D, STAI, PMS
49	Hayden et al., 2012	USA	Dementia	Psychoeducation with peer support	Process evaluation on recruitment	N/A	57 (57)	Recruitment challenges	Recruitment rate & obstacles
50	Kajiyama et al., 2013	USA	Dementia	Psychoeducation	RCT	Information-only	150	Stress, bother, depression	PSS-10, RMBPC, CES-D
51	Kwok et al., 2014	Hong Kong	Dementia	CBT	Pre-post evaluation	N/A	36	Distress, self-efficacy	NPI-Q, RSCSE
52	Lai et al., 2013	Hong Kong	Dementia	Psychoeducation with peer support	RCT	Face-to-face support	11	Depression, burden, knowledge	CES-D, ZBI, ADKT
53	Lewis et al., 2010	USA	Dementia	Psychoeducation	Usability test	N/A	63	Feedback, usability, clarity	Questionnaire
54	Mahoney et al., 2003	USA	Dementia	Counselling with peer support	RCT	Information booklet	100	Bother, anxiety, depression	RMBPC, SAI, CES-D
55	Marziali and Garcia, 2011	Canada	Dementia	Psychoeducation with peer support	Evaluation study	Online text-based chat group	91	Distress, neuroticism, self-efficacy, health status	SMAG, EPO-R, RSCSE, HSQ-12
56	McKechnie et al., 2014	UK	Dementia	Network support	Pre-post evaluation	N/A	69	Anxiety, depression	GAD-7, PHQ-9
57	Núñez-Naveira et al., 2016	Spain, Denmark & Poland	Dementia	Psychoeducation with peer forum	RCT	TAU	77	Depression, competence, satisfaction	CES-D, CCS, RCSS

(*continued on next page*)

Table 1 (*continued*)

Study no.	Study author(s) & year published	Country	Target LTI	Intervention approach	Study design	Comparison (if used)	Carer sample size (PS)	Primary outcome	Outcome measure
58	O'Connor et al., 2014	USA	Dementia	Psychoeducation with peer support	Pre-post evaluation	N/A	7	Stress, depression, loneliness	PSS, ZBI, GDS, UCLA-LS
59	Pagan-Ortiz et al., 2014	USA	Dementia	Psychoeducation	Quasi-randomized study	Written information	32	Burden, perceived social support, distress	ZBI, LSNS, CES-D
60	Pot et al., 2015	Netherlands	Dementia	Same as study 33	Process evaluation	N/A	[Same sample as study 33]	Acceptability, usage, feedback	Usage data, questionnaire
61	Rentz and Von Hoene, 2010	USA	Dementia	Psychoeducation & coaching	Usability evaluation	N/A	121	Usage, feedback	Usage data, questionnaire
62	Schaller et al., 2015	Germany	Dementia	Psychoeducation	Pilot evaluation	N/A	31	Satisfaction, perceived support	Interview
63	Schaller et al., 2016	Germany	Dementia	Same as study 62	Pre-post evaluation	N/A	25	Empowerment, QoL, burden	CNA-D, EQ-5D, BSFC
64	Torkamani et al., 2014	UK, Spain & Greece	Dementia	Psychoeducation with social networking	RCT	TAU	60 (60)	Distress, health status, burden	NPI, EQ5D, ZBI
Studies on cancer (65–70)									
65	Cernvall et al., 2015	Sweden	Cancer	Psychoeducation	RCT	Waitlist	58	PTSS symptoms, depression, anxiety	PCL-C, BDI-II, BAI
66	DuBenske et al., 2014	USA	Lung cancer	Psychoeducation	RCT	Internet use only	246 (246)	Quality of life, negative mood	CQoL-C, POMS
67	Namkoong et al., 2012	USA	Lung cancer	Same as study 66	Secondary process evaluation		[104 carers from study 66)	Factors affecting usage and coping	PCBS
68	Northouse et al., 2014	USA	Cancer	Psychoeducation	Pre-post evaluation	N/A	38 (38)	Distress, QoL, Communication	PMS, FACT-spouse version, MISS
69	Scott and Beatty, 2013	Australia	Cancer	CBT	Pre-post evaluation	N/A	13	Negative affect, distress, PTSD symptoms, QoL	DASS-SS, CSD, PTSS-SR, EORTCQLQ-C30
70	Song et al., 2015	USA	Prostate cancer	Psychoeducation	Pre-post evaluation	N/A	26 (26)	Quality of life, relationship, communication	FACT-Spousal version, RAI, MISS
Studies on medical conditions (71–74)									
71	Fidika et al., 2015	Germany	Cystic fibrosis	Writing therapy	Pre-post evaluation	N/A	31	Anxiety, depression, QoL	HAD, CES-D, Ulm QoLI
72	Lichenstein et al., 2013	USA	Pulmonary hypertension	Peer discussion forum	Qualitative study	N/A	98	Usage, nature of posts	Usage data, forum posts
73	Piette, Striplin, et al., 2015*; Piette et al., 2015	USA	Chronic heart failure	mHealth network care package	RCT	Interactive voice response calls	372 (372)	Strain & burden, depression, acceptability	CSI, CES-D, qualitative feedback
74	Swallow et al., 2015*; Swallow et al., 2016	UK	Chronic kidney disease	Psychoeducation with peer support	Feasibility RCT	TAU	55	Empowerment, family management	FSSS-ES subscale, CMAS
Studies on general disability and unspecified long term illness (75–78)									
75	Barbabella et al., 2016	Italy, Germany & Sweden	Elderly with multiple chronic illness	Psychoeducation with peer forum	Pre-post evaluation	N/A	123	Wellbeing, perceived impact, social support, usage data	COPE, MSPSS
76	Dew et al., 2004	USA	Heart transplant	Psychoeducation with peer support	Prospective cohort study	Historical dyad data	60 (64)	Anxiety, hostility, QoL, usage, feedback	SCL-90, SF-36, interview
77	Klemm et al., 2014	USA	Unspecified chronic illness	Psychoeducation with peer support	RCT	Online peer support group	47	Depression, burden, QoL	CES-D, CSI, CQoLI
78	Torp et al., 2013	Norway	General disability	Network support augmenting face-to-face events	Post-use focus group	N/A	17	Usability, acceptability	Focus group

LTI = Long term illness, (PS) = patient sample if included, N/A = not applicable, *denotes the major publication for the study, TAU = treatment as usual, [n] denotes same sample drawn from another study, RCT = randomized controlled trial, STDS = State Trait Depression Scale, STAI = State Trait Anxiety Inventory, FSCI = Family Stress & Coping Interview, HADS = Hospital Anxiety & Depression Schedule, ECI = Experience of Caregiving Inventory, EE scale = Expressed Emotion scale, GHQ-28 = General Health Questionnaire-28 items, FMI = Family Member Impact scale, CQ = Coping Questionnaire, SRT = Symptom Rating Test, RDRD = Ratings of Disease-Related Distress, WEI = website Evaluation Instrument, SSRS = Social Support Rating scale, SIPA = Stress Index for Parents of Adolescents, DSC-10R = Distress Symptom Checklist-10R, ZBI = Zarit Burden Inventory, PHQ-9 = Patient Health Questionnaire-9, GAD-7 = General Health Questionnaire-7, SCL-90 = Global Severity of Symptom Checklist 90-R, CES-D = Centre for Epidemiologic Studies Depression Scale, SWLS = Satisfaction with Life Scale, MCAS = Modified Caregiver Appraisal Scale, SSS-11 = 11-item Social Support Survey, SPSI-R:S = Social Problem Solving Inventory–Revised Short Form, CES = Care Effectiveness Scale, CSES = Caregiving Self-Efficacy Scale, GAS = Goal Attainment Scale, BSFC = Burden Scale for Family Caregivers, PSS-14 = Perceived Stress Scale,

RSCSE = Revised Scale for Caregiving Self-Efficacy, RMBPC = Revised Memory and Behaviour Problems Checklist, ISI = Insomnia Severity Index, SGS = Stress-related Growth Scale, CAI = Caregiver Appraisal Inventory, PMS = Pearlin's Master Scale, PSS-10 = 10-item Perceived Stress Scale, NPI-Q = Neuropsychiatric Inventory Questionnaire, ADKT = Alzheimer's Disease Knowledge Test, SAI = State Anxiety Inventory, SMAG = Functional Autonomy Measurement System, EPO-R = Eysenck Personality Questionnaire-Revised, HSQ-12 = Health Status Questionnaire-12, CCS = Caregiver Competence Scale, RCSS = Revised Caregiving Satisfaction Scale, PSS = Perceived Stress Scale, GDS = Geriatric Depression Scale, UCLS-LS = UCLA Loneliness Scale, LSNS = Lubben Social Network Scale, CNA-D = Carers' Needs Assessment for Dementia, EQ-5D = EuroQoL 5 dimensions questionnaire, PCL-C = PTSD Checklist Civilian Version, BDI-II = Beck Depression Inventory, BAI = Beck Anxiety Inventory, CQoL-C = Caregiver Quality of Life-Cancer Scale, POMS = Short Version Profile of Mood States, PCBS = Perceived Carer Bonding Scale, FACT = Functional Assessment of Chronic Illness Therapy (FACT)-Spousal version, MISS = Mutuality & Interpersonal Sensitivity Scale, DASS-SS = Depression Anxiety Stress Scale-Stress subscales, CSD = Cancer-Specific Distress, PTSS-SR = PTSD Symptom Scale-Self-Reported version, EORTCQLQ-C30 = European Organisation for Research & Treatment of Cancer Quality of Life Core Questionnaire, RAI = Relationship Assessment Scale, Ulm QoLI = Quality of Life Index for parents of chronically ill children, CSI = Caregiver Strain Index, FSSS-ES = Family Scale Service System–Empowerment Subscale, CMAS = Condition Management Ability Scale, COPE = 5-item WHO Wellbeing Index, Carers of Older People in Europe Index, MSPSS = Multidimensional Scale of Perceived Social Support, SCL-90 = Symptom Checklist-90, SF-36 = Short Form-36, CQoLI = Caregiver Quality-of-Life Index.

eligibility criterion, but spouses and children turned out to be the majority of recipients.

3.2. Study designs and study aims

We broadly categorised study designs into five types as follows (see Table 2):

(1) Effectiveness (or efficacy) studies (26 studies, 33%) including RCTs and quasi-experimental studies. These studies aimed to establish the intervention effectiveness for carers' outcomes, comparing to usual care received (such as conventional face to face therapy or support) or an active comparison (such as a text-based bibliotherapy) (e.g. studies 5 & 74).
(2) Evaluation studies (24 studies, 31%) including uncontrolled or single-group before-after studies. These non-comparative studies tended to pilot-test the intervention effectiveness for pre-specified carer's outcomes using a within-subject pre-post design (e.g. studies 37 & 75).
(3) Feasibility or usability studies (10 studies, 13%) including most commonly post-use surveys or studies evaluating usability of the intervention. These studies aimed to establish the ease of use and perceived acceptability of the intervention (e.g. studies 10 & 38).
(4) Qualitative studies (7 studies, 9%) including most commonly post-use individual interview or focus group studies, or qualitative analysis on narrative data collected by the intervention platforms (e.g. studies 19 & 72).
(5) Other studies (11 studies, 14%) including mixed-method studies documenting the development and pilot-testing of the intervention, or its prototype. Think-aloud usability tests (Jerz, 2000; Shackel, 1990), feedback collected using questionnaires and/or interviews were examples of study methods commonly employed in this category (e.g. study 41 & 62).

3.3. Carer outcomes and measures

The outcomes reported across studies varied widely, as did the use of measures and/or tools (see Table 1). Study aims differed across the five main categories of study designs, as did the carer outcomes. For instance, for effectiveness/efficacy trials aiming to establish the impact of eHealth intervention on carers' outcomes, the most common outcomes targeted, were carers' depression, anxiety, burden and distress/health morbidities. The Centre for Epidemiologic Studies Depression Scale (CES-D, Radloff, 1977), Patient Health Questionnaire-9 (PHQ-9, Spitzer, Kroenke, & Williams, 1999), Zarit Burden Inventory (ZBI, Zarit, Orr, & Zarit, 1985), and Caregiving Self-Efficacy Scale (CSES, Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002) were the most commonly used measures which are validated and widely-used in studies across illness types (e.g. studies 5, 23, 43 & 73). However, some studies used disease-specific measures investigating similar constructs. Examples included: Carers' Needs Assessment for Dementia (CNA-D, Wancata et al., 2005); and Cancer-Specific Distress (CSD, Herschbach et al., 2004), used for carers of dementia (studies 50 & 52) or cancer patients (study 69) respectively. Other frequently reported primary and/or secondary outcomes included carers' knowledge, coping, self-efficacy and perceived social support. Evaluation studies (e.g. studies 17, 36, and 69) also commonly reported outcome measures used in effectiveness/efficacy trials, as aforementioned.

In feasibility/usability studies, pre-intervention/baseline measurements were often not taken. Instead, these studies primarily aimed to establish the perceived acceptability or carers' experience in using the intervention, through descriptive survey questionnaires or interviews (e.g. studies 10, 25& 42). Researcher-devised (largely un-validated) questionnaires or interview topic guides and usage data analysis was commonly used to glean insight into the accessibility, likeability, usability, usefulness, utility and acceptability of the intervention and how

Table 2
Study designs used by the included studies according to LTI categories.

LTI category	Effectiveness studies	Evaluative studies	Feasibility studies	Qualitative studies	Other studies	No. of studies	No. of interventions	No. of papers
Mental illness	3	4	3	2	1	13	12	14[a]
Neurological conditions	7	4	4	2	1	18	12	18
Dementia	11	10	3	1	8	33	25	33
Cancer	2	3	0	0	1	6	5	6
Medical conditions	2	1	0	1	0	4	4	6[a]
Other	1	2	0	1	0	4	4	4
Total	26	24	10	7	11	78	62	81

[a] Two papers reported on the same study.

carers used it in real life context (Jerz, 2000; Shackel, 1990).

Qualitative study designs, such as individual interviews (e.g. studies 12, 35) and focus groups (e.g. study 78), were most commonly used to explore carers' experience and perceived acceptability of the interventions. In a few studies, qualitative data collected as post/discussion content or carers' experiences made on the forums which formed part of the intervention (studies 8 and 39), were analysed to illustrate the theoretical framework underlying the match or mismatch of user characteristics and usage pattern.

Lastly, we grouped studies using mixed methods, and not fitting any of the above study designs, into the fifth category. These studies (e.g. studies 7 & 41) commonly documented the development of and initial testing of the intervention (prototypes). Iterative consultations with users, mostly carers, patients and clinicians, were frequently used along the intervention development process. Instead of testing the intervention (or its prototype) in remote or online studies as described in usability studies, methods such as 'walk through exercises' and 'think aloud sessions' were often used. Carers tried out an on- or off-line version of the intervention in research facilities, observation on carers' usage and carers' feedback were then used to inform the intervention development and refinement (Jerz, 2000; Shackel, 1990).

As all the included interventions were delivered at least in part through a web-based platform, usage data (e.g. number of log-ons, time of use, pattern of usage) were always collected and stored by an online platform. In contrast, outcome data were collected via conventional formats (such as face to face interviews or postal questionnaires) (e.g. 32, 37, 40, and 57) or online media (studies 10, 75, and 77), in equal measures. Only two studies reported using eHealth (i.e. video-simulation tests where participants were quizzed with a video imitating real life family caregiving situation or scenario, study 21) or mHealth (i.e. sleep actigraphy band, study 45) technology to collect outcome data alongside the intervention delivery.

3.4. Intervention approaches

In terms of intervention approaches, there were: 19 online therapies (including psychoeducation, CBT, e-coaching for carers) (e.g. studies 5 & 30); seven stand-alone peer support or networking interventions (such as online forum for carers, e.g. studies 4 & 56); 28 interventions which combined both online therapy and network support with other carers (studies 10, 48 & 75); four other online interventions (such as online journaling exercises, online clinical guideline, e.g. studies 1 & 15) including the only mHealth care support package intervention (study 73); and four eHealth elements augmenting face-to-face treatment (such as family therapy, e.g. studies 2 & 43). See Table 1 for intervention approaches used by the included studies.

3.5. ICT features and elements of eHealth interventions

The majority of interventions used two (16 interventions, 26%) or more (32 interventions, 52%) modes of delivery as outlined by Webb and colleagues' coding system (Webb et al., 2010). Fourteen interventions used only one mode of delivery (23%), either an enriched information environment (e.g. studies 7, 15 & 53) or an unmoderated network support platform (e.g. studies 4 & 56). Three quarters of the interventions provided an enriched information environment (48 interventions, 77%), and many of these also used additional delivery modes across categories to optimise the interactions and communicative functions (e.g. studies 10 & 74). Peer-to-peer discussion boards or forums were the most common communication functions reported (34 interventions, 55%), very often moderated by healthcare professionals working as an online facilitator rather than non-moderated (i.e. no one in post to facilitate discussion or monitor the post content). Access to clinicians, experts or advisors was also available in 17 interventions (27%, e.g. studies 10 & 23), with an additional nine interventions included scheduled contacts with experts or advisors (15%, e.g. studies 5 & 31). In terms of supplementary modes, phone calls and/or smart phone messages originating from forums or discussion boards were most commonly reported (31 interventions, 50%, e.g. studies 43 & 45). Ten interventions used emails (16%, e.g. studies 36, 37 & 73), eight used videoconferencing (13%, e.g. studies 13, 14, 20, 28, 30, 32, 48 & 75), and one (2%) each used skype (study 22) or avatar (study 58). Ten interventions delivered using videoconferencing, skype or avatar (altogether 16%) formed the minority of synchronous delivery while the majority of interventions did not require live participation (i.e. these were asynchronous). Mode of delivery employed by the included interventions are summarised in Table 3.

3.6. Intervention duration and intensity

Intervention duration and intensity varied widely between studies. Most interventions did not stipulate the usage requirement, and instead suggested that carers use the intervention as preferred; there was no prescribed "dosage" or intensity per se. This type of self-paced access and usage was particularly common for intervention development process studies, feasibility/usability studies and qualitative studies (e.g. studies 10, 13, & 35). Interventions offering network support frequently did not specify the minimal required usage, and thus, registered carers could participate in forum communications as much or as little as they liked (e.g. studies 11 & 56). In effectiveness and evaluation studies where carers' outcome data were collected and compared pre- and post-intervention use, a recommended/structured programme of sessions over the study period and follow-up time points was relatively more common. A typical example included a four-month CBT intervention called "Overcoming Anorexia Online (OAO)" offering eight weekly self-guided and clinician-guidance sessions through an enriched online environment over 18 weeks (studies 5 & 6). For studies which specified intervention duration and intensity, interventions took place over five consecutive days (study 15) and up to two years (study 66). As aforementioned, asynchronous intervention delivery was much more common than live delivery, allowing carers flexibility in terms of the intervention frequency and intensity.

Table 3
Modes of delivery used by included interventions.

Study No.	Intervention approach	Automated functions			Communicative functions			Supplementary modes				
		(a) Enriched environment	(b) Tailored feedback	(c) Follow-up messages	(d) Access to advisor	(e) Scheduled advisor contact	(f) Peer-to-peer access	(g) Email/ forum platform	(h) Phone (including SMS)	(i) Skype	(j) Video-conferencing	(k) Avatar
Online therapy with or without network support as indicated by communication functions used												
3	Psychoeducation	x			x		x		x			
9	Psychoeducation	x					x		x			
10	Psychoeducation	x			x		x		x			
13	Psychoeducation				x		x				x	
14	Psychoeducation	x				x					x	
17	Skill workshop			x			x					
20 (16, 19)	Psychoeducation	x					x				x	
23 (24–26)	Psychoeducation	x			x				x			
27	Psychoeducation	x					x					
28	Psychoeducation				x						x	
29	Psychoeducation	x					x	x				
32	Psychoeducation	x			x						x	
33 (60)	Psychoeducation		x		x							
34 (35)	Psychoeducation	x			x		x		x			
37 (38, 39)	Psychoeducation	x			x			x				
40 (41)	Psychoeducation	x										
44	Psychoeducation						x		x			
45	Psychoeducation	x			x		x					
46 (47)	Psychoeducation	x					x		x			
48	Psychoeducation	x				x	x				x	
49	Psychoeducation	x			x				x			
50	Psychoeducation	x										
52	Psychoeducation						x		x			
53	Psychoeducation	x										
55	Psychoeducation	x					x	x	x			
57	Psychoeducation	x					x		x			
58	Psychoeducation					x	x					x
59	Psychoeducation	x			x		x		x			
63 (62)	Psychoeducation		x						x			
64	Psychoeducation	x					x		x			
65	Psychoeducation		x									
66 (67)	Psychoeducation		x		x		x		x			
68	Psychoeducation		x					x				
70	Psychoeducation	x										
74	Psychoeducation	x					x		x			
75	Psychoeducation	x			x		x	x			x	
76	Psychoeducation	x			x		x		x			
77	Psychoeducation						x		x			
61	Psychoeducation & coaching		x			x		x				
5 (6)	CBT		x			x		x	x			
36	Coaching		x			x	x	x	x			
51	CBT			x		x						
69	CBT	x										
7	5-step method therapy	x										
22	Problem-solving therapy	x				x				x		
30 (31)	Problem-solving therapy	x				x					x	
54	Counselling	x			x		x		x			
Stand-alone network support interventions												
4	Network support						x		x			
8	Network support							x	x			
11	Network support						x		x			
12	Network support	x			x		x		x			
18	Network support						x					
56	Network support						x		x			
72	Network support						x		x			
Other interventions												
1	Guideline	x										
15	Writing therapy			x								
71	Writing therapy		x									
73	mHealth network care package		x					x				
eHealth intervention elements adjunct to face-to-face therapy												
2	Adjunct with FT						x		x			

(*continued on next page*)

Table 3 (*continued*)

Study No.	Intervention approach	Automated functions			Communicative functions			Supplementary modes				
		(a) Enriched environment	(b) Tailored feedback	(c) Follow-up messages	(d) Access to advisor	(e) Scheduled advisor contact	(f) Peer-to-peer access	(g) Email/ forum platform	(h) Phone (including SMS)	(i) Skype	(j) Video-conferencing	(k) Avatar
21	Legislative advocacy training	x										
43 (42)	Augmented FT								x			
78	Augmented network support	x					x		x			

SMS = short message service, (study no.) = associated studies/papers reporting on the same intervention, CBT = cognitive behavioural therapy, FT = family therapy.

3.7. Overall study quality

Our evaluation of the included study quality and the comparison of the global ICROMS score of each study against the ICROMS minimal score requirement for the specific study design is presented in Table 4. For the 26 effectiveness/efficacy studies, their ICROMS global quality score ranged from 13 to 31 (mean = 23.4, median = 24.5, ICROMS minimal score requirement = 22). The 24 evaluation studies commonly used controlled or non-controlled before-after design and had a global score on the ICROMS criteria ranging from 7 to 25 (mean = 18.6, median = 19, ICROMS minimal score requirement = 22). Ten were feasibility or usability studies using commonly post-use survey questionnaire design; global quality scores ranged from 12 to 21 (mean = 16.4, median = 16.5, ICROMS minimal score requirement = 16). There were seven qualitative studies with ICROMS global scores ranging from 16 to 22 (mean = 19.6, median = 20, ICROMS minimal score requirement = 16). Lastly, the global quality scores of the 11 studies using mixed methods to develop and/or pilot-test the intervention-prototypes ranged from 13 to 22 (mean = 18.2, median = 20, ICROMS minimal score requirement = 16). Using the ICROMS minimal score requirement of specific study designs, we rated 44 studies (56%) as meeting the minimal quality score requirement; 34 (44%) falling short of it. Common reasons that reduced the study quality were small and unjustified sample size and sample selection (e.g. $n = 5$ in study 26, $n = 7$ in study 58), use of un-validated outcome measures (e.g. on usability, perceived acceptability) and poor analysis rigour. For effectiveness/efficacy and evaluation trials, completion rate varied across studies with the lowest reported being 38% (study 69 due to intervention design not focused on carers) and 39% (study 66 due to huge loss of patients due to death from cancer) to beyond 80% (e.g. studies 17, 21, 32, 46 & 73). For studies reporting a below 80% completion rate (i.e. the common standard used to judge study quality), analysis using completers' data only rather than intention-to-treat principle (e.g. study 13, 50, 51, 58, 64, 66, 69, 71) might carry additional bias, in particular, over-estimated positive effect size of the intervention (Moher et al., 2009).

3.8. Carers' experience and perceived acceptability of interventions

In general, carers' perceived acceptability of the eHealth interventions across the studies synthesised was high (studies 1–3, 10, 11, 20, 24–28, 35, 42, 48, 52, 53, 56–58, 60–63, 70, 72, 73, 76, 78). Common elements of the interventions that were repeatedly highlighted and attributed to high satisfaction included: flexibility in access suiting carers' lifestyles and commitments; availability of self-tailored and -paced programme allowing for individualised information and support; and network support through online forums with other carers and access to professionals. These desirable intervention and delivery features were concurred by carers across rural (e.g. remote areas in Canada or Europe, studies 55 & 78) and urban (e.g. Hong Kong, studies 3, 51, 52) geographical areas. Without corroboration from validated outcome data, most carers also subjectively identified that the online intervention helped them cope with the stress of caregiving.

Conversely, a few studies reported difficulties in even recruiting and retaining carers due to obstacles of access, cost, and time regarding use of technology (studies 6, 49, 65 & 69). Most studies included focused on carers of dementia patients, and this was also the area with the most frequently reported problems in access and usability, as encountered by a group of largely elderly spousal carers who were often not familiar with ICT. In a small number of studies (e.g. 49, 75), despite extensive recruitment efforts and provision of equipment and technical support, recruitment and completion rates still struggled as some carers reported finding it difficult to strike up a rapport with the professionals and their carer-peers and would still prefer the conventional delivery media using face to face group or individual meetings (Studies 16 & 41). Usability problems (such as oral communication/chat quality, audio-visual function failure) were also identified as attributing to high drop-out rates (up to 50%) in some studies (e.g. studies 7, 37, 47 & 50).

3.9. Treatment effects of eHealth interventions

Overall, there was substantial heterogeneity across included studies, including variations in the populations, intervention design and delivery, and use of a wide range of outcome measures. Further, outcomes were measured at different time points (ranging from one week to two years), rendering most results across studies incomparable. As a result, we did not consider it appropriate to conduct a meta-analysis using subgroup data (e.g. population groups or illness conditions).

As quantitative data could not be statistically combined for meta-analyses, extracted outcome data from the 50 effectiveness/efficacy and evaluative studies were synthesised into a narrative summary herewith. Sixteen studies (32%) reported significant positive effects on carers' outcomes including health morbidities and caregiving experiences, burden, perceived social support, self-efficacy, and quality of life (e.g. studies 5, 28–29, 71 & 73). These studies focused on carers of individuals with mental illness (3 studies), neurological conditions (4 studies), dementia (4 studies), cancer (3 studies) and medical illness (2 studies). Interventions evaluated included online CBT (e.g. study 5), advocacy skills training or coaching (studies 17, 21, 36), psychoeducation with or without peer support (e.g. studies 28, 29, 34, 55, 66, 68, & 70), writing therapies (study 71), and online support groups adjunct to face to face family therapy (studies 2 & 43). Twelve studies (24%) reported that compared to the active intervention, usual care or no treatment had more favourable outcomes. Two studies evaluated network support or CBT for mental illness carers (studies 4 & 6); five reported on psychoeducation or problem-solving therapy for neurological conditions carers (studies 15, 20, 22, 23 & 30); four on psychoeducation for dementia carers (studies 37, 40, 54 & 59); and one on CBT for cancer carers (study 69). Lastly, 22 studies (44%, studies 9, 13, 14, 18, 32, 33, 44–46, 50–52, 56–58, 63–65, 74–77) reported equivocal findings: while carers reported positive experiences in using the interventions, no significant changes in their outcomes were identified post intervention or

Table 4
Quality assessment of included studies using ICROMS.

Study design category & study name	Study design	Aims & justification	Sampling	Outcome measures	Follow up	Other study aspects	Analytical rigour	Other considerations	Global quality score
Effectiveness/efficacy studies									
Blom, 2015	RCT	2	4	6	6	2	2	9	31
Candell, 2003	RCT	2	2	4	3	1	1	6	19
Cernvall, 2015	RCT	2	4	3	6	2	2	8	27
Cristancho-Lacroix, 2015	RCT	2	4	4	6	2	2	8	28
DuBenske, 2014	RCT	2	3	4	5	2	1	8	25
Eisdorfer, 2003	RCT	2	2	4	6	2	2	7	25
Finkel, 2007	RCT	2	2	5	5	2	2	7	25
Fowler, 2016	RCT	2	2	4	3	1	1	7	20
Grover, 2011b	RCT	2	4	6	5	2	1	9	29
Hoyle, 2013	RCT	2	2	4	6	2	2	6	24
Kajiyama, 2013	RCT	2	2	5	5	2	1	7	24
Klemm, 2014	RCT	2	2	4	4	1	1	6	20
Lai, 2013	RCT	2	1	0	4	1	1	4	13
Marziali, 2006	RCT	1	1	4	2	1	1	5	15
Mahoney, 2003	RCT	2	4	6	5	2	1	8	28
McLaughlin, 2013	RCT	2	3	6	3	2	1	8	25
Núñez-Naveira, 2016	RCT	2	2	3	2	1	1	7	18
Pagan -Ortiz, 2014	qRCT	1	2	5	0	1	1	5	15
Petranovich, 2015	RCT	2	4	6	4	2	1	9	28
Pierce, 2009	RCT	2	3	3	5	1	0	6	20
Piette, 2015a	RCT	2	4	4	6	2	2	8	28
Rotonti, Haas, et al., 2005	RCT	2	2	3	5	2	1	6	21
Smith, 2012	RCT	2	4	4	6	2	2	8	28
Swallow, 2015	RCT	2	4	3	6	2	2	8	27
Torkamani, 2014	RCT	2	2	4	2	2	1	7	20
Wade, 2012	RCT	2	3	3	6	2	1	7	24
Evaluation studies									
Antonini, 2012	NCBA	4	1	2	2	3	1	7	20
Austrom, 2015	NCBA	2	1	0	1	1	1	1	7
Barbabella, 2016	CBA	4	2	3	2	2	2	8	23
Berk, 2013	SS	5	2	1	2	2	2	8	22
Binford Hopf, 2013	NCITS	4	2	4	1	2	2	2	17
Blusi, 2014	NCBA	4	2	2	2	1	1	6	18
Boots., 2016	NCBA	4	1	2	0	2	1	6	16
Chiu, 2009	NCBA	3	1	3	2	2	1	7	19
Clifford, 2013	CBA	2	1	5	2	2	1	7	20
Dew., 2004	CS	2	2	5	2	1	1	8	21
Fidika, 2015	NCBA	5	2	3	2	3	2	8	25
Glueckauf, 2004	NCBA	4	2	3	1	1	1	6	18
Kwok, 2014	NCBA	4	2	3	1	2	1	6	19
Lorig, 2012	NCBA	4	2	2	2	2	2	5	19
Lucas, 2011	OS	2	1	0	0	1	1	4	9
Marziali, 2011	CBA	2	2	6	1	1	2	7	21
McKechnie, 2014	CS	4	2	3	2	2	1	6	20
Northouse, 2014	NCBA	5	1	1	3	1	1	7	19
O'Connor, 2014	NCBA	4	2	3	2	1	1	5	18
Sander, 2009	SS+QS	4	1	1	2	2	1	6	17
Schaller, 2016	NCBA	4	2	3	1	3	1	8	22
Scott, 2013	NCBA	5	1	3	1	2	1	6	19
Song, 2015	NCBA	5	2	3	2	1	1	7	21
Zimmerman, 2014	NCBA	5	1	0	2	1	1	6	16
Feasibility or usability studies									
Chan, 2016	SS	3	1	1	1	1	1	6	14
Chiu, 2010	CS	2	1	3	2	1	1	7	17
Czaja, 2002	SS	4	2	1	1	1	1	6	16
Pierce, 2004	SS+QS	3	1	0	1	2	1	6	14
Pierce, 2002	SS	3	1	1	1	2	1	5	14
Rentz, 2010	CS	3	1	1	1	1	1	4	12
Rotondi, Sinkule, et al., 2005	NCBA	3	1	3	2	2	1	6	18
Sin et al., 2014	SS	5	2	1	2	2	2	7	21
Stjernsward, 2011	OS	5	2	1	2	2	1	7	20
Wade, 2008	NCBA	2	1	3	2	2	1	7	18
Qualitative studies									
Blusi, 2013	QS	5	2	2	1	2	2	7	21
Damianakis, 2016	QS	4	1	1	2	1	2	7	18
Lichenstein, 2013	QS	4	2	2	1	2	2	7	20
Marziali, 2005	QS	5	2	2	1	2	2	8	22
Perron, 2002	QS	4	1	1	1	2	2	7	18
Torp, 2013	QS	5	2	2	2	2	1	8	22
Trondsen, 2014	QS	4	2	1	2	1	1	5	16
Other studies									
Chiu, 2011	QS	6	2	2	2	2	1	7	22
Cristancho-Lacroix, 2014	OS	5	1	2	2	2	1	7	20
Glueckauf, 2003	OS	2	1	2	2	1	1	4	13
Griffiths, 2016	OS	5	2	2	2	2	1	7	21
Hayden, 2012	OS	3	2	1	2	1	1	5	15
Ibanga, 2010	OS	3	1	1	1	1	1	5	13
Lewis, 2010	SS	4	2	2	2	2	1	6	19
Namkoong, 2012	OS	4	2	3	2	2	1	7	21
Pierce, 2013	OS	3	2	1	1	1	1	5	14
Pot, 2015	OS	4	2	2	2	2	1	8	21
Schaller, 2015	OS	5	2	2	1	2	1	8	21

Study designs (& ICROMS minimal score requirement): (q)RCT = (Quasi) randomised controlled trial (22); CBA = controlled before-after (18); NCITS = non-controlled interrupted time series (22); NCBA = non-controlled before-after (22); CS = cohort study (18); QS = qualitative study (16); SS = survey study (16); OS = other design (16)

Comparison against minimal score requirement: below requirement or met or above requirement

at follow-up time points. These studies spanned across the six LTI categories, although heavily featured interventions targeting dementia carers (13 studies). Psychoeducation with or without peer network support was most frequently evaluated (18 studies) whilst there were two studies testing stand-alone network support and CBT respectively.

Of note, while outcomes evaluated were largely similar across studies, scales used varied. Similarly, subtle differences were also noted in terms of intervention approaches across LTI categories. For instance, psychoeducation for physical LTI often covered more practical caring skills, such as symptoms monitoring, treatment administration and communication with professionals (alongside support on appraisals of caregiving experiences); such content were less prominent in equivalent interventions targeting carers supporting an individual with a mental illness. Methodologically, there were a higher proportion of RCTs (9 out of 12 studies, 75%) among the studies reporting negative results; compared to those reporting neutral (11 out of 22 studies, 50%) or positive (6 out of 16 studies, 38%) carers' outcomes.

4. Discussion

To the best of our knowledge, this is the first systematic review about eHealth (and mHealth) interventions focusing on carers of individuals with a broad range of LTI. Our search was comprehensive of 7016 papers, we identified and included 81 papers which described 78 unique studies. The number of studies published during the past 15 years suggests that eHealth interventions for carers are rapidly developing. Overall, 26 studies were RCTs seeking to test the effectiveness/efficacy of the eHealth interventions; the remaining studies (67%) primarily used uncontrolled designs, providing evaluations of the feasibility and acceptability of interventions, or descriptions of intervention development. This suggests the field, albeit fast-evolving, is still in its infancy with the research focus largely placed on intervention innovation and usability evaluation to date.

Importantly, the review findings indicate that eHealth interventions are largely well-received by carers, across different LTI, population demographics and geographical areas. Carers perceived that the flexibility, self-paced nature and individualised programme of information and support of eHealth interventions, to be uniquely advantageous. Carers also appreciated the network support function, which was a common feature integrated in many interventions, through an online carer forum and/or a space to consult health care professionals. Compared with interventions delivered via face-to-face formats, the design and development of eHealth interventions appears to include more user input (Adenuga, Kekwaletswe, & Coleman, 2015; Shackel, 1990). Iterative consultations and/or participative research with carers (and patients) as end-users, and health care professionals as providers/facilitators, were frequently conducted and reported to inform intervention development (Barry & Edgman-Levitan, 2012). Further, we identified usability studies/tests as a unique health study design in the field of ICT interventions/applications. eHealth/mHealth interventions are designed to be used autonomously by users in their own natural context, and so their accessibility, utility, ease of use and likeability are paramount (Andrews & Titov, 2010; Shackel, 1990).

A wide range of intervention approaches was reported. These included CBT, counselling, problem-solving skills training, coaching, advocacy training, stand-alone network support with fellow-carers, and writing/journal therapy. Psychoeducation, with or without a peer support forum, was the most common eHealth intervention across LTI types. However, despite overlaps, it is apparent that interventions differed in a range of characteristics, such as in terms of duration, intensity, the number of sessions (i.e. distinct topics covered) and degree of professional/clinical guidance (if used). It is possible that these differences are attributed to the fact that optimal treatment formats differ according to the clinical condition and carer characteristics (e.g. parent-carers for paediatric patients vs. spousal carers for people with dementia). As such, and reflecting evidence from other interventions, it may be that one format is insufficient for addressing carers' needs across LTI types.

In general, study quality for nearly half of the studies was poor, with many falling short of expected study reporting standards. Although we used the ICROMS as a comprehensive study quality assessment tool, there remains a mismatch between study quality standards and innovative study designs used in the field, such as usability tests. On the one hand, it could be argued that e(&m)Health interventions are inherently advantageous in delivering standardised content and upholding fidelity of intervention content/procedures given the whole or majority of the pre-set intervention content is delivered directly to the participants from its web-based platform (Christensen et al., 2009; Powell et al., 2013). And yet on the other hand, despite some studies have pre-specified the minimal intervention exposure required of their participants (e.g. Rotondi, Haas, et al., 2005; Rotondi, Sinkule, et al., 2005), the participants have the flexibility to choose their own adherence or rather, non-adherence. A further quality issue raised here concerns retention and completion rates in eHealth intervention trials. Paradoxically, carers are encouraged to use eHealth interventions as they wish to, while their usage is expected to meet a pre-specified amount or timepoint in order that intervention effectiveness can be evaluated (Eysenbach, 2005; Powell et al., 2013). The below-80% completion rate and the lack of available data for non-completers may have compromised, and thereby biased the study results. These methodological variations further limit the evidence about effects (and adverse events) of eHealth interventions for carers (Musiat, Goldstone, & Tarrier, 2014; Alvarez-Jimenez et al., 2014). Despite the widely proposed advantage of eHealth interventions as being low-cost (Andrews & Titov, 2010; Powell et al., 2008), no health economic data were available.

4.1. Strengths and limitations

This review was planned and conducted according to PRISMA guidelines. We believe our search was comprehensive and exhaustive, including grey and unpublished sources, as well as multiple electronic databases and manual hand searches. We included all study designs in order to scope comprehensively the state of art in the field. The review solely included papers written in English (and Chinese if found), but we did not exclude any studies due to the fact they were not published in English. However, it is possible, despite our extensive search, publications in other languages might have been inadvertently omitted. Also, interventions developed and tested may not have been reported as a scientific study; a well-known phenomenon in a field that is arguably driven by commercial developers as opposed to clinical-academic researchers (Kumar et al., 2013; Meurk, Leung, Hall, Head, & Whiteford, 2016; Musiat et al., 2014). Moreover, some eHealth intervention trials targeting health morbidities in the general population (e.g. the MoodGym studies in Australia and the UK, Christensen, Leach, Barney, Mackinnon, & Griffiths, 2006; Powell et al., 2013), may have included carers, but not reported these data separately. Most studies were conducted in English-speaking Western cultures. This means that caution should be exercised in generalising the review's conclusions to non-English speaking countries, particularly low and middle-income countries where mHealth applications are deemed more accessible and convenient (Estrin & Sim, 2010; Kahn, Yang, & Kahn, 2010; Labrique, Vasudevan, Kochi, Fabricant, & Mehld, 2013).

4.2. Future directions

More studies on eHealth and mHealth interventions for carers of people with LTI are needed to better understand intervention efficacy and effectiveness, as well as the factors associated with positive and equivocal outcomes. Research findings to date suggest that eHealth interventions are sought by carers, and deemed acceptable. Further studies should seek to exploit the unique features of eHealth

interventions, and optimise user-participation in intervention development and feasibility/usability-testing (Christensen et al., 2009; Sin, 2013). Considering the quality issues noted here, and the challenges in pooling data, which is both clinically and methodologically heterogeneous, future studies should pay attention to research quality aspects and develop carer-focused interventions more rigorously. Important aspects include: performing power calculations to ensure that studies have adequate sample sizes; listing pre-specified primary outcomes that are congruent to the increased understanding of carers' priorities; using well-validated outcome measurements; presenting results from intention-to-treat analyses; and clearly specifying rates of adherence and attrition (Eysenbach & CONSORT-EHEALTH Group, 2011). Also, studies should exploit the vast amount of accessibility and usage data, which are automatically collected and stored via online platforms hosting eHealth interventions. Analysis strategies should explore outcome data depending on usage patterns and user characteristics, to better understand how carers engage with different aspects of online or mobile interventions over time (Christensen, Griffiths, & Korten, 2002; Sin et al., 2014; Powell et al., 2008). Studies comparing with face-to-face interventions are needed in order to investigate the relative effectiveness or equivalent of these modes of treatment. Similarly, design, content and interface aspects of interventions should be carefully analysed to tease out their potential differential effects (Alvarez-Jimenez et al., 2012; Kumar et al., 2013).

Furthermore, considering that this is a rapidly expanding field, it will be timely for future reviews to be health condition specific, especially in those areas where there was a larger body of studies (e.g. dementia). Those future reviews might usefully focus on effectiveness studies and, as such, should pay closer attention to quality (as detailed above) in order to make more robust assessments of intervention effect, perhaps allowing for meta-analysis. Importantly, these insights will enable us to identify user and intervention variables associated with uptake and treatment effects, so to inform the optimal design of future novel interventions.

5. Conclusions

Large numbers of family and friends who provide care for a loved one with an LTI, need, and benefit from, support for themselves. Our review findings indicate that eHealth interventions for carers are becoming more popular, and these are generally perceived as acceptable, desirable and helpful. Further research in the field is needed. Such endeavours should focus on maximising internal validity of studies, in addition to investigating interactions between carers' characteristics, intervention design and intended usage patterns. Better understanding of these factors should enhance the optimal design of interventions, leading to improved accessibility, engagement and importantly, carers' outcomes.

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Contributions of authors

Jacqueline Sin: conception and design of the protocol, search, screening and assessment of studies, data extraction, quality assessment, analysis and interpretation of data, writing and reviewing the paper.

Claire Henderson: protocol design, supervision of the review, writing and reviewing the paper.

Debbie Spain: protocol design, screening of search results, quality assessment, and reviewing the final paper.

Victoria Cornelius: protocol design, reviewing the analysis and reviewing the final paper.

Tao Chen: protocol design, reviewing the analysis and reviewing the final paper.

Steve Gillard: protocol design, quality assessment, supervision of the review, writing and reviewing the paper.

All authors contributed to and have approved the final manuscript.

Conflict of interest

All authors declare no conflict of interest.

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