Type of Paper – Review

Title – Internet-based interventions for carers of individuals with psychiatric and neurological disorders and brain injury: A systematic review

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Summary

Background – Non-professional caregivers who provide support to an individual with a psychiatric or neurological disorder will often themselves experience symptoms of stress, anxiety, and low mood, and perceive that they receive little support. Internet-based interventions have previously been found to be effective in the treatment and prevention of a range of mental health difficulties.

Objectives – The current review seeks to investigate the status of existing internet-based interventions for informal carers of people with psychiatric and neurological disorders or traumatic brain injury, establishing the degree to which they improve carer mental health.

Methods – A systematic literature search was conducted in October 2017 using the Embase (1974 – present), Ovid MEDLINE (1946 – present), PsychARTICLES, PsychINFO (1806 – present) and Global Health (1973 – present) databases, via the Ovid Technologies database. Search terms included carer, caregiver, online, technology, web-based, interactive, intervention, and evaluation.

Studies selected for inclusion in this review met the following predetermined criteria: (i) delivering an intervention aimed primarily at informal (non-professional) caregivers; of (ii) individuals with psychiatric disorders, stroke, dementia, or brain injury; (iii) the intervention delivered to the caregivers was primarily internet-based; (iv) the study reported a pre- and post- quantitative measure of caregiver depression, anxiety, stress, burden, or quality of life; (v) appearing in a peer-reviewed journal; and (vi) accessible in English.

Results – A total of 39 studies were identified for inclusion through the detailed search strategy. The search was conducted and data information extracted independently by two researchers. Studies were found to vary greatly with regards to both methodological quality, and reported efficacy/effectiveness of the intervention on measures relating to caregiver mental health, however, the majority of studies
did report that one or more measures relating to carer mental health was found to improve following receipt of a relevant intervention.

**Conclusions** – Studies investigating internet-based interventions for carers of individuals with psychiatric and neurological difficulties and brain injury show some evidence in support of the effectiveness of internet-based interventions, and additionally, that such interventions are likely to be found acceptable by the caring population. The evidence currently available within this field is of varying quality, and has some methodological shortcomings. Further research in this area is required to establish how specific components, such as the structure and interactivity of the intervention, may contribute to the overall efficacy of the intervention with regards to carer mental health, and how this frequently underserved population can best be supported.

**Keywords** – Internet; caregivers; mental health; technology; review

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Introduction

Non-professional (or informal) caregivers are individuals who provide care for another person (usually a family member or friend), free of charge, who would not be able to cope without their support. Informal caregivers play a crucial role in providing both practical and emotional care for individuals with a wide range of difficulties, including physical and mental health difficulties, disabilities, or problems with addiction.

It is estimated that during 2015, 6.8 million people in the UK provided unpaid care to a close other, a 16.5% increase from 2001, reflecting an economic value of informal carers of £132 billion per year, almost double the value in 2001 [1]. Additionally, as the support of informal caregivers may reduce and delay the rate of hospital admissions [2], this may help reduce the burden on overstretched healthcare systems.

It has been widely documented that caring for a loved one with a long-term illness can have a multitude of effects on the informal carer, including increased levels of perceived burden [3], feelings of entrapment, shame, and guilt [4], and higher rates of physical symptoms, such as fatigue, headaches, and weight loss [5].

It is important to recognise the differences in how caregivers of individuals with various types of difficulty perceive their experience of caregiving. Differences in symptoms, in addition to societal reactions to differing pathologies will doubtlessly impact the carers’ experience of caregiving [6]. For example, when comparing carers of people with schizophrenia and carers of people with long-term physical disorders, levels of subjective burden were found to be higher in carers of people with schizophrenia and brain diseases, than in other groups [6]. Furthermore, levels of social support available to carers of individuals with schizophrenia were found to be lower than for carers of individuals with physical disorders.

Previous work reviewing the evidence regarding the impact of internet interventions on caregiver stress, for carers supporting a loved one with a broad range of mental and physical illnesses (including dementia, cancer, mental health difficulties, and hip fractures) were mostly positive, with some mixed findings [7,8]. The present review focuses specifically on caregivers of people with psychiatric
disorders, neurological disorders (dementia, stroke) and brain injury. In contrast with other recent reviews investigating carer internet-based interventions, we have made the decision to restrict our inclusion criteria to carers of individuals with these disorders specifically, as the burden of caring for someone whose primary difficulty relates to their cognitive abilities and/or mental health, may be vastly different from that of caring for someone whose condition primarily impacts on their physical health (for example, cancer).

Developing a greater understanding of the efficacy of web-based interventions for such caregivers may help guide the development and refinement of future interventions for this group, who may have different needs to caregivers of people with physical health conditions.

Importance of Internet-Based Interventions

A range of carer-focussed interventions have been found to reduce psychological distress, and improve the quality of life of individuals caring for people with severe mental health difficulties [9]. However, due to the nature of caregiving, and associated time constraints, some carers may find it difficult to access face-to-face services, and may additionally have concerns regarding privacy or stigma [10].

In recent years, internet usage has continued to increase across adults of all ages, with 87.9% of UK adults using the internet over a three-month period in 2016, compared to 86.2% in 2015 [11]. For the majority of UK individuals, internet usage has become a regular activity, blending seamlessly into their lives.

Internet-based interventions have been found to be effective in the treatment and prevention of a range of psychiatric disorders, including depression [12], anxiety [13], post-traumatic stress disorder (PTSD) [14], and eating disorders [15]. As caregivers often experience elevated levels of depression and stress, and reduced general well-being [16], internet interventions to improve carers’ own mental health should be considered as a potentially viable option.
As technology continues to advance at a rapid pace, what constitutes an ‘internet-based intervention’ today is highly likely to change over the course of just a few years. For some of the older studies included in this review, the technology utilised to provide the intervention may already be considered by some to be out of date. Taking this into consideration, for the purpose of this review, we have decided to include both those studies where the intervention is primarily based on a website (typically accessed by use of a browser on a personal computer, laptop, tablet, or smartphone), and those primarily delivered via videoconferencing technology. Although there are significant differences between websites and videophones as vehicles for intervention delivery, both require the utilisation of an internet connection, and, unlike calling a landline or mobile phone, videophone technology allows for a considerably more interactive experience, and easier access to video elements in addition to audio.

Internet Interventions for Carers of People with Psychiatric and Neurological Disorders and Brain Injury

Online information, education, support, and skills-training can be found in many forms; supportive forums or chatrooms, informative websites, links to service providers, embedded video or audio features, news articles, or live-chats via internet-based applications. In recent years, researchers and clinicians have begun to take advantage of the flexibility of internet-based interventions, with a number of studies beginning to document the efficacy of internet-based interventions designed to improve carer mental health.

As carers face a multitude of difficulties, some studies focus on whether online interventions can help increase carer knowledge of their loved one’s disorder [17], or teach skills to contribute to change behaviour of the carers’ loved one (for example, children with attention-deficit hyperactivity disorder (ADHD), [18]. The current review focusses on whether online interventions can improve carer mental health, and has therefore only included studies taking a quantitative measure of mental health (specifically; depression, anxiety, stress, burden, or perceived quality of life). 39 studies have been
identified through the literature search; a summary of these studies is given in Multimedia Appendices 1, 2, 3, 4, and 5, and further details can be found below.

Objectives

This systematic review seeks to investigate the current status of existing internet-based interventions for informal carers of people with mental health and neurological difficulties, by establishing:

- The number of studies investigating the efficacy or effectiveness of online interventions for carers of people with different types of mental health or neurological difficulties.
- The impact that such online interventions have on measures of carer mental health – depression, anxiety, stress, burden, or quality of life.
- Where applicable, how online interventions compare to other intervention types (e.g. care as usual, face-to-face interventions).
- The quality and validity of existing studies investigating the efficacy or effectiveness of online carer interventions.

Methods

Eligibility Criteria

The papers selected for inclusion in this review met the following predetermined criteria: (i) delivering an intervention aimed primarily at informal (non-professional) caregivers; of (ii) children or adults with psychiatric disorders, stroke, dementia, or brain injury; (iii) the intervention delivered to the caregivers was primarily internet-based; (iv) the study reported a pre- and post- quantitative measure of caregiver depression, anxiety, stress, burden, or quality of life; (v) appearing in a peer-reviewed journal; and (vi) accessible in English.

Studies were excluded if the intervention was aimed exclusively at the patient rather than the caregiver. Papers exclusively reporting other measures of intervention efficacy (e.g. increase in caregiver knowledge) were also excluded from this review.
Information Sources

A systematic literature search was conducted in October 2017 using the Embase (1974 – present), Ovid MEDLINE (1946 – present), PsychARTICLES, PsychINFO (1806 – present) and Global Health (1973 – present) databases, via the Ovid Technologies database. Searches of reference lists of articles listed in this review, and relevant review papers were also conducted. Five papers identified in the literature search which could not be obtained were requested from their authors via ResearchGate. Of these, two authors responded by sending over the full text of their study to be assessed for eligibility. The search was limited to papers that could be accessed in English.

Search Strategy

Search terms were; (carer OR caregiver OR care-giver OR carers) AND (online OR on-line OR technology OR web-based OR interactive OR internet) AND (intervention OR evaluation). This search strategy returned 39 studies that met each of the inclusion criteria detailed above.

Data Collection Process

A data extraction sheet (adapted from the Cochrane Consumers and Communication Review Group’s data extraction template) was developed and pilot-tested on five, randomly-selected studies, to be included in the review, and refined accordingly following the pilot-testing.

Data were extracted from the included studies by one study author (LS), and checked by a second author (RP). Disagreements between reviewers were resolved by consensus. No authors were contacted for further information.

Data Items

For each study within the review, we extracted participant characteristics (number per study arm, average age, gender), details of the web-based intervention (including intervention name, content,
average number of sessions, and duration), and details of the control group where applicable.

Regarding study findings, we extracted data regarding the significance of quantitative findings of carer psychological health, and the timepoints at which outcome data was collected. Additionally, we identified the primary outcome(s) where this was specified, and extra data regarding any qualitative findings with particular relevance to carer outcomes / mental health.

Rating Evidence of Intervention Effectiveness

Each of the studies included in the review was rated on the effectiveness of the intervention employed, in terms of the extent to which the intervention had a positive impact on outcomes relating to caregiver depression, anxiety, stress, burden, or quality of life. Studies were given one of three ratings, as described below;

- Intervention shows clear association with positive outcomes relating to caregiver depression, anxiety, stress, burden, or quality of life. **Effectiveness of intervention score = 3.**
- Intervention shows some association with positive outcomes relating to caregiver depression, anxiety, stress, burden, or quality of life. **Effectiveness of intervention score = 2.**
- Intervention shows very little or no association with positive outcomes relating to caregiver distress, anxiety, stress, burden, or quality of life. **Effectiveness of intervention score = 1.**

Risk of Bias in Individual Studies

Risk of bias within individual studies was rated independently by two researchers (LS and RP). Randomised controlled trials (RCTs) were assessed using the following criteria to give an overall risk of bias and determine study quality rating; whether the study employed a randomised controlled trial design, sample size n > 30 in each study condition, an a priori power analysis, lack of recruitment (selection) bias, similarity of groups at baseline, reporting of drop-outs, drop-out rate < 20%, utilisation of intent-to-treat analysis, reporting of all relevant outcomes, use of validated and reliable outcome measures, adequate method of randomisation, allocation concealment, blinding of assessors, registration in clinical trial registry, good adherence to intervention protocols, representative population, relevance of intervention, clinically relevant primary endpoint(s). Disagreements were resolved by discussion.
Of the 39 studies identified for inclusion in the review, 25 were RCTs, and were rated in terms of their quality. Of these 25 RCTs, 14 were rated as high quality, and 11 as moderate quality.

**Study Selection**

Eligibility assessment for each study to be included in the systematic review was performed independently by two reviewers (LS and RP), using the eligibility criteria detailed above. Disagreements between reviewers were resolved by consensus. A search of Embase, Ovid MEDLINE, PsychARTICLES, PsychINFO and Global Health returned a total of 3456 studies. 5 additional citations were identified through searching the reference lists of relevant papers. After adjusting for duplicates, 2923 studies remained. Of these studies, 2703 were excluded following a review of their abstracts, as they did not appear to meet the inclusion criteria detailed above. The full text of the remaining 220 studies was examined in detail. Of these studies, a further 181 were excluded, with reasons for their exclusion being detailed in Table 1. This left a total of 39 studies to be included in the review. A flow diagram detailing the selection of studies for inclusion can be found in Figure 1.

<table>
<thead>
<tr>
<th>Reason for Exclusion</th>
<th>Number</th>
</tr>
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<tbody>
<tr>
<td>Review article</td>
<td>24</td>
</tr>
<tr>
<td>Does not report an intervention</td>
<td>10</td>
</tr>
<tr>
<td>Qualitative data only</td>
<td>16</td>
</tr>
<tr>
<td>Carer recipient not suffering from mental health, dementia, stroke or brain inj.</td>
<td>21</td>
</tr>
<tr>
<td>Unable to access</td>
<td>12</td>
</tr>
<tr>
<td>Not available in English</td>
<td>4</td>
</tr>
<tr>
<td>Not an article in a peer-reviewed journal</td>
<td>26</td>
</tr>
<tr>
<td>Does not report pre/post measure of burden, stress, depression, anxiety, or QoL</td>
<td>23</td>
</tr>
<tr>
<td>Study protocol</td>
<td>11</td>
</tr>
<tr>
<td>Does not report an internet-based intervention</td>
<td>27</td>
</tr>
<tr>
<td>Intervention aimed at sufferer rather than carer</td>
<td>5</td>
</tr>
<tr>
<td>Professional caregivers</td>
<td>2</td>
</tr>
</tbody>
</table>

**Table 1** – Reasons for exclusion of studies examined in detail (n = 181).
Figure 1 – Flow chart detailing study selection for the review
Results

Study Quality

Of the 39 studies identified meeting the inclusion criteria, 25 consisted of randomised controlled trials, and were ranked on their quality using the criteria detailed above. Of these 25 studies, 14 were found to be of high quality and 11 of moderate quality.

Psychiatric Disorders

Studies regarding caregivers of individuals with psychiatric disorders are summarised in Multimedia Appendix 1. A total of 11 studies were identified as meeting the inclusion criteria. For the purpose of this review, studies are grouped and discussed below by specific disorder (Anorexia Nervosa, Schizophrenia / Schizoaffective disorder, ADHD, and studies describing mixed mental health difficulties).

Anorexia Nervosa

Two RCTs explored the efficacy of a sequential, 8-modular (with participants completing approximately one module per week) online intervention (Overcoming Anorexia Online; OAO), based upon a systemic, cognitive-behavioural therapy (CBT) framework, in supporting carers of adults with AN. In a study rated to be of high quality, comparison of carers receiving OAO with those receiving support as usual from the charity B-eat, OAO was found to reduce levels of carer anxiety and depression to a greater extent than support as usual [19].

In a later study, rated to be of moderate quality, the OAO intervention with clinician guidance was compared with OAO without additional guidance [20]. No significant improvements were found in either group over time, with regards to carer anxiety, depression, or stress. Improvements over time were observed across other measures (including negative experiences of caregiving and intrusiveness), although these findings were mixed with regards to whether additional clinician support improves outcomes.
**Depression**

In a highly rated RCT, participation in a self-management intervention ‘E-care for caregivers’ for a period of 6 weeks [21], was not found to be associated with a decrease in symptoms of carer distress. However, the intervention was rated as user-friendly by participants, indicating that the further development and implementation of internet-based interventions may be acceptable to carers of individuals with depression.

**Schizophrenia/Schizoaffective Disorder**

The efficacy of a telehealth intervention (‘The Schizophrenia Guide’) of three months duration, for individuals with schizophrenia (or schizoaffective disorder) and their caregivers was compared within an RCT with care as usual, in a study considered to be of moderate quality. Although no between-group differences were found with regards to levels of perceived carer stress, individuals with schizophrenia allocated to the intervention group were found to display reduced stress levels [22].

A later study also investigated the efficacy of an online, multifamily intervention [23], compared to support as usual in a quasi-experimental trial, conducted over a period of 12 months. This study also failed to discover a difference in levels of carer distress between intervention and control groups, using a slightly larger sample (n = 42) and longer study duration (12 months). However, family relationship stress improved over time in the intervention group, and the majority of users expressed high levels of satisfaction with the online intervention.

**ADHD**

Investigating the impact of an 8-session, psychoeducational parenting programme, delivered via videoconferencing technology, a small case series (n=8) found improvements in both parent distress, and child behaviour, over time [18]. In a recent study, (during which participants received 6 sessions, over an intervention period of 25 weeks) videoconferencing technology to deliver caregiver behaviour training (alongside pharmacotherapy) was compared with the same intervention content, delivered in-
person to participants [24]. However, while families in both conditions reported similar levels of improvement in their child’s level of functioning, and comparable satisfaction, carers allocated to the teletherapy group did not report improvements in their own mental health, while those in the in-person group did.

**Mixed Mental Health Difficulties**

Recent research has begun to examine online carer interventions which, through providing more general support and information, may be useable by carers of individuals suffering from a broad range of mental health difficulties.

Stjernswärd and Hansson [25], in a study rated to be of high quality, compared a 10-week online mindfulness program with a wait-list control, in adult carers supporting people with a wide range of diagnoses (including depression, anxiety disorders, psychosis, and autism spectrum disorders), and found that, in addition to an improvement in mindfulness, those in the intervention group also reported a reduction in perceived stress, and some aspects of quality of life / carer burden.

The same authors have additionally reported results of a pre-post comparison, in which participants completed an 8-week web-based mindfulness program [26]. Similarly to the results of the RCT, improvements were found in carer quality of life / burden, perceived stress, and mindfulness. These improvements were largely maintained at follow-up.

A recent pre-post comparison study [27] targeting carers of adolescents with mental health problems, found that a 3-month intervention powered by a Moderated Online Social Therapy (MOST) software platform, was acceptable and safe for use by participants, and that after engaging with the programme, participants showed a significant reduction on a measure of stress, although other measures relating to carer mental wellbeing (depression, anxiety, and psychological wellbeing) did not find a significant change at the end of the intervention.

While the majority of carer interventions currently appear to focus on adult carers, it is also important to consider specific needs of younger people caring for a family member.
A recent RCT (considered to be of high quality), comparing the effectiveness of a web-based intervention with ‘folder support’ (participants in this condition were provided with a folder, containing information on available support services) for young carers of individuals with mental illness, found mixed results regarding the efficacy of the online intervention [28]. No between-group differences were observed with regards to carer stress, and although both groups displayed an increase in well-being, only the ‘folder’ group displayed improvements in carer self-efficacy and quality of life.

**Stroke**

In recent years, the number of stroke survivors and overall global burden of stroke have been increasing [29], with the vast majority of stroke survivors living at home in the years following their stroke [30]. Informal caregivers of stroke survivors have been found to have high levels of depressive symptoms [31], and burden [32] in the months and years post-stroke. Thus, there is a considerable need for innovative interventions to support this population of caregivers.

Four studies (summarised in Multimedia Appendix 2) were identified which test web-based interventions for carers of stroke survivors [33, 34, 35, 36]. Two of these were RCTs and rated as high quality, with the other two studies [33, 36], consisting of pre-post comparisons.

Differing in duration from 4 weeks [33], to 18 months [36], each of the four interventions provided relevant informative resources, in addition to contact with fellow carers and professionals through a range of channels, including email, message boards, online chats, telephone, and videophone.

With regards to quantitative measures of psychological functioning, two of the four studies found no significant change in measures of depression, life satisfaction [34], burden, or mental health [36] in participants receiving the respective online interventions. Smith and colleagues [35], however, found a significant improvement in reported depression (including a clinically meaningful change) in the intervention group over time, while Graf et al., [33] reported a decrease in both depressive symptoms and burden, regardless of total number of years spent caregiving.
Dementia

As the worldwide population of older people grows, so does the global prevalence of dementia; 46.8 million people were living with dementia in 2015, a number which is estimated to rise to 74.7 million by 2030 [37]. As the disease progresses, people with dementia may display a range of behavioural and psychological symptoms, including apathy, irritability, misidentification of people and objects, depression, hallucinations, and persecutory delusions [38]. Given these difficulties, it is unsurprising that informal carers are found to have elevated levels of depressive symptoms and stress, in comparison with non-carers [16].

Within the scope of this review, studies documenting internet interventions for carers of people with dementia were found to be the most prevalent, with a total of 17 studies eligible for inclusion, consisting of 10 studies featuring a control group for comparison (Multimedia Appendix 3), and 7 studies without a control group (Multimedia Appendix 4). Intervention duration varied from 30 days [39], to 12 months [36, 40, 41]. Of the studies featuring a control group, 3 were rated as high quality, 6 as moderate quality, and 1 was not rated due to employing a quasi-experimental design (see Multimedia Appendix 3).

Again, these studies reported mixed findings with regards to the effectiveness of the interventions on measures of carer mental health, with 5 of the studies reporting mostly or all positive findings, 6 reporting mixed findings, and 6 reporting that the online interventions did not have a positive impact on carer mental health. Interestingly, the interventions reporting the positive findings tended to be those of shorter duration, with 4 of the 6 lasting 9 weeks or less [39, 42, 43, 44].

It is also of interest to note that the two studies with the largest sample size [10, 39], both reported positive findings, and both employed an RCT design. In contrast, many of the studies failing to find a positive impact of online interventions on carer mental health utilised smaller sample sizes, however, these findings should be interpreted with caution given the potential lack of statistical power.
Traumatic Brain Injury

Traumatic brain injury (TBI) is a non-degenerative, acquired brain injury, which may significantly impact both sufferers and those around them. An estimated 1.1% of the US population was found to be living with a long-term disability resulting from TBI in 2005 [45], a condition associated with a range of social, behavioural, and academic difficulties [46, 47, 48]. Both adults with TBI and their caregivers have been found to display significant symptoms of depression [49].

The current review found 8 studies meeting the inclusion criteria for carers of people with TBI (Multimedia Appendix 5). Of these studies, 7 featured interventions aimed specifically at carers of children and adolescents with TBI. All of these featured self-guided, modular interventions, followed by either a videoconference or Skype session with a therapist.

Interventions varied in duration from 10 days [50], to 6 months [51, 52, 53], although a number of studies did not specify the length of the intervention.

Findings with regards to the effectiveness of these interventions were mixed, with one study reporting mostly or all positive findings, 6 reporting mixed findings, and one reporting negative findings. The one intervention reporting negative findings [50] was the shortest, the only study not aimed specifically at carers of children and adolescents, and its primary focus was on improving family advocacy.
Discussion

This systematic review identified 39 studies investigating online interventions for carers of individuals with psychiatric disorders, stroke, dementia, and traumatic brain injury, with regards to their efficacy in improving or maintaining a range of facets of carer mental health. Below, findings for each of the different disorders are discussed in turn.

Psychiatric Disorders

Eleven studies investigated the impact of an internet-based intervention on caregivers of individuals with a range of psychiatric disorders, including anorexia nervosa, depression, schizophrenia, ADHD, and mixed mental health difficulties. People with these different disorders present with varying needs and support requirements and thus different challenges for their carers, making comparisons across disorders difficult. Moreover, study and intervention design vary considerably across studies, all of which potentially affects outcomes. Aspects of an intervention which may influence the impact of a specific intervention may include; whether or not the intervention is theory-driven and based on a specific model of carer distress, or alternatively, how else the intervention content and format was decided upon (for example; focus groups, literature reviews or clinician / researcher opinion), whether the intervention is delivered via a website, or other internet-based technology (such as videoconferencing), whether the intervention is modular and sequential, or allows unstructured exploration of a website, the extent to which the intervention is interactive (e.g. is feedback given to participants on their knowledge, symptoms or any other characteristics), whether and how it is supported, e.g. can participants interact with one another, or communicate with clinicians / researchers, and additionally, does the intervention contain elements other than text – such as video or audio features). Possible future research directions are considered for each disorder below, but there is also a clear need for additional research given the small number of studies available,

Anorexia Nervosa
Both studies concerning carers of individuals with anorexia, tested aspects of the same intervention (OAO), which was derived from a model of carer distress, co-produced with carers, experts by experience, and professionals within the field [54]. In the first of these the online intervention delivered with support from experienced clinicians and was found to improve carer distress compared to usual support [19]. In the second study, which was small and underpowered, the addition of limited support by a trainee psychologist had no advantage over online intervention alone [20]. Taken together these findings demonstrate that OAO can provide benefits for carer mental health, over and above the support typically offered to carers of individuals with AN. However, the impact of additional clinician support is currently unclear. This may be due in part to factors pertaining to the study methodology, including small sample size (n = 37), guidance being provided by trainee clinicians, with limited experience in the field of eating disorders, and the follow-up period (3-months) possibly being too short for carers to have fully honed and applied the skills taught within the programme.

Future research in this area should seek to establish the additional benefit (if any) of clinician support and whether any observed differences were maintained at longer-term follow-up. Additionally, it would also be useful to extend this work to carers of individuals diagnosed with other eating disorders, such as bulimia nervosa or binge eating disorder.

**Depression**

Only one study [21] assessed the efficacy of an internet-based intervention for carers of people with depression. The intervention was interactive and modular, and based on psychoeducation and CBT techniques. Despite high reported levels of user-friendliness the intervention was ineffective. Of note over 50% of participating carers kept their study participation a secret from the person they cared for, in order to protect them. It is possible that this high degree of secretiveness contributed to the lack of efficacy of the intervention as it would have made it harder for participants to alter their behaviour and apply skills learnt via the online package, and may thus inadvertently maintain the illness and
carers’ own distress. Future interventions for carers of people with depression may need to address and remedy these issues.

Schizophrenia / Schizoaffective Disorder

Two studies focused on carers of individuals with schizophrenia; one was a small underpowered RCT of moderate quality [22], and the other employed a quasi-experimental design [23].

The intervention reported in the Rotondi and colleagues’ study [22] was a website accessed by the individual with schizophrenia, in addition to their carer. Whilst this is an interesting idea, it would be important to establish whether an intervention based on an evidence-based model of distress targeted at carers specifically is more effective than one targeting both the individual with schizophrenia, and their carer, as these two groups may have different needs. Furthermore, although both interventions permitted interaction with fellow participants, neither employed a modular approach – it may be helpful for future research in this area to establish whether a more structured approach may be associated with improvements in carer mental health. Additionally, it may be helpful to establish whether the observed improvements in family relations may lead to improvements in carer mental health, if they are maintained over a longer period of time.

ADHD

Neither of the two studies of interventions for carers of individuals with ADHD were RCTs; in a small case series [18] the group Triple P Parenting Program showed promise in reducing carer distress. A second study [24] involved a subset of data drawn from a larger study comparing the same intervention face-to-face or delivered via teletherapy. Carer distress only improved in the face-to-face delivery group. Whilst these findings are somewhat promising, as a next step RCTs are needed to further elucidate the role of online interventions in supporting carers of people with ADHD.

Qualitative data from carers may help explore carers’ views on the relative merits of face-to-face vs online interventions, as in the Tse et al study [24], only carers receiving in-person training displayed
improvements in their reported stress levels, although the content was the same in the online intervention. Interventions in both studies appear to be based behavioural and developmental models relating to ADHD, however, it may be helpful for future research to establish whether videoconferencing is the most effective way to deliver training to carers (in comparison, for example, with a website, where carers are able to work through, and re-visit, the materials at their own pace).

**Mixed Mental Health Difficulties**

Four studies featured online interventions for carers of individuals with mixed mental health difficulties; two of which [25, 28] were RCTs, and two were pre-post comparisons [26, 27] with some evidence of reducing carer distress. These interventions were either co-designed with potential intervention users [27, 28], or based pragmatically on use of mindfulness [25, 26] – a technique which has been widely utilized across a range of population groups.

In future, it may be useful to compare disorder-specific carer interventions with more generic ones, potentially applicable to carers of people with a broad range of disorders to assess their relative merits in relation to their ability to improve carer outcomes.

**Stroke**

Two of the four studies providing an online intervention for carers of stroke survivors were high quality RCTs [34, 35], with the remaining two studies [33, 36], consisting of relatively small sample sizes (n=19 and n=72, respectively) in pre-post comparison studies.

Of the four studies, only two [33, 35] found a positive impact of their interventions on carer mental health. There may be a number of reasons for this disparity in findings – only the studies by Smith [35] and Graf [33] delivered information to participants in a sequential, modular way. Particularly for older carers, who may have less experience in navigating websites, a more structured intervention may be more accessible. Furthermore, the study by Torp and colleagues [36] included carers of
individuals with dementia, as well as carers of stroke survivors, which may have resulted in the content of the intervention being less tailored to the specific needs of stroke carers.

Although the findings relating to carer mental health provide a mixed picture regarding the effectiveness of the online interventions, such interventions have been found to have other positive effects, including carers perceiving greater social support following an online intervention [36], and stroke survivors whose carer received an online intervention requiring fewer emergency department visits and fewer hospital readmissions than those whose carer did not, reducing the burden on the health service [34]. Future research in this area should seek to explore which particular aspects of an online intervention lead to specific improvement across a wide variety of carer outcomes.

**Dementia**

A large number of studies investigated the effectiveness of online interventions for carers of individuals with dementia, reflecting the size of this problem and the very major consequences for carers.

As noted above, there is some evidence that the shorter interventions may have appeared to be more effective than those of longer duration. This may seem surprising as dementia is a chronic condition. However, the apparent effectiveness of shorter interventions in comparison with those of longer duration may reflect that, over the course of the longer interventions, the symptoms of the person with dementia may worsen, causing their caregiver to experience elevated levels of stress and burden.

Whilst of the five studies finding positive results, three did not feature a control group, two very large RCTS did find evidence of the effectiveness of their interventions [10, 39], which indicates that benefits of online interventions for carers of people with dementia are solid.

There may be a number of reasons why these studies found mixed results regarding caregiver mental health – it may be the case that, over time, the dementia survivors’ condition worsened, resulting in their carer experiencing a greater sense of burden and related symptoms of mental distress, or that having increased knowledge of the aftermath of dementia survival may lead carers to a greater appreciation of the present and future difficulties they and their loved one may have to face.
It is also of interest to note the disparate methods by which the interventions for dementia carers were developed. While some appeared to be based to a greater or lesser extent on existing theories of (for example), stress and coping [39], the content of others was derived from interviews with carers and reviews of the relevant literature [44], despite both interventions being found to be effective with regards to measures of carer mental health. Future research into this area may want to investigate the feasibility of developing a model of carer distress specific to those supporting someone with dementia, which could potentially incorporate aspects of existing theories, in addition to being co-produced with carers.

As people with dementia are often cared for by their older spouses, who may be unfamiliar with internet usage, and/or may have visual or hearing impairments, it is important to consider the appropriateness of online interventions for this particular population, and how such internet-based interventions may benefit from being altered to fit the specific needs of older caregivers. Several of the studies in this review used videoconferencing technology as part of their intervention – future research may wish to establish whether being able to see other carers, or clinicians, is more helpful to this population than interacting with a computer screen alone, as findings from the current review are inconclusive with regards to this issue.

**Traumatic Brain Injury**

Similarly to the findings relating to other disorders, the 8 studies identified as evaluating an online intervention for carers of people with TBI found mixed results, although it is of interest to note that all of these 8 studies utilized an RCT design (with 5 studies rated as being of high quality, and 3 of moderate quality).

As the only study that did not find any improvement in carer mental health outcomes [50] was primarily aimed at improving family advocacy, it is worth considering that interventions may need to be focussed specifically at improving mental health in order to see improvements in these areas, rather than targeting skill-building or problem-solving. This study additionally differed from the rest as the
website consisted of links and articles, as opposed to carers following a self-guided, modular intervention, followed by online interaction with a therapist.

In the future, it would be useful to establish whether either or both of these aspects – a structured, modular program (as opposed to a site containing links, which the carer is required to navigate without guidance), or support by a clinician, are particularly associated with more positive psychological outcomes in carers.

It is also of interest to note that the majority of the TBI-carer interventions reported on within this review were to some extent developed with reference to family problem solving therapy. This shared element may indicate that these interventions are to some extent more homogenous, when compared with those developed for carers of people with other psychiatric or neurological disorders, (where interventions targeting the same populations have been developed from a wider range of sources, models, and theories).

As most current studies on carer interventions for people with TBI have focused on children and adolescents, future research should seek to address the needs of carers of adults with TBI.

General Discussion

The field of online mental health interventions is still relatively new, and continues to develop rapidly, including the recent recognition of the potential of online interventions specifically aimed at carers.

Studies in this review focus on carers of individuals with a range of difficulties including psychiatric disorders, neurological disorders, and brain injury, with diverse challenges for carers. Unsurprisingly therefore the format, content and nature of interventions used here varies widely. Nonetheless, the evidence-based relating to some areas (dementia, TBI) is much more solid (with 5 and 4 large scale RCTs (> 100 participants) respectively) than in other areas (stroke, psychiatric disorders), where there are only 1 or 2 large scale RCTs respectively. Across all areas findings in relation to reductions of carer distress are somewhat mixed. This may largely be to do with differences in populations and aspects of study design. In addition, not all of the studies presented focused primarily on carer
outcomes, and several interventions with little or no impact on carer distress had other benefits (e.g. improvements in patient outcomes).

Currently the jury is still out as to whether interventions specifically designed with a particular disorder in mind and based on a clear model of carer distress have advantages over more generic ‘off-the-peg’ interventions. Of note, in the area of TBI several successful interventions consisted of some kind of problem solving approach, and in the area of mixed mental health problems mindfulness approaches were successfully used.

A further possible factor in explaining the differences observed in the efficacy of the different web interventions presented here, may be the wide range of initiatives encompassed by the phrase ‘internet based’ (for example, interactive web-sites accessed in the carers own home, versus videoconferencing chat, accessed from a local clinic). As the development of technology continues at an increasing pace, what may currently constitute a typical internet-based intervention, may appear out-dated in just a few short years.

**Limitations**

Several key limitations need to be noted. Firstly, as this field is a currently emerging area, a significant proportion of the studies included consist of single-arm, pre-post trials, with no randomization or control group comparisons. For those studies (RCTs, clinically controlled trials where we were able to do a quality assessment, this varied widely, with some of the studies lacking key information on randomization methodology, blinding of assessors, and not having an accessible study protocol. This increases the difficulty of assessing the risk of bias within studies, and makes it harder to interpret the effectiveness of the intervention reported.

Finally, due to the wide range of outcomes employed across studies to measure change in carer mental health and related constructs, we were unable to conduct a meta-analysis of the data, making it more difficult to interpret and compare findings across studies.
Future Considerations

Although the studies detailed above present a mixed picture regarding the overall effect of online interventions on carer mental health, participating carers consistently reported that they found online interventions to be highly acceptable, and easy to utilise, where these data were gathered. This may indicate that carers are willing to integrate web-based interventions into their daily lives, and future research should attempt to establish the most effective way of delivering content to have the greatest impact possible on carer mental health.

As described above, internet-based interventions can consist of many different components, and it would be beneficial for future research to establish the degree to which particular elements contribute to forming an effective intervention. For example, it would be useful to be able to establish the active components of a given intervention, so findings can be more easily accumulated and compared across interventions, improving the evidence-base regarding which components of an intervention lead to desired behaviour change [55]. The possibility of establishing specific models of carer distress on which interventions can be built, should also be taken into consideration, in addition to consulting additional sources of information (such as focus groups, expert opinion, and reviews of the relevant literature).

Future work into the impact of caring carer-interventions should consider taking a life-span approach when considering the challenges of caring, both in terms of the carer life stage (for example, the differing requirements of young carers and older spousal carers), and that of the individual being cared for, and how these challenges can change and develop over time.

Consideration (including with regard to cost-effectiveness) should also be given to the possibility of ‘blended’ care, where carers would receive some face-to-face clinician contact, in addition to accessing an online intervention.
Conclusions

The emerging field of internet-based interventions for carers of individuals with psychiatric disorders, neurological disorders, and brain injury offers exciting possibilities for providing support to a population who may otherwise find it difficult to access support. While findings from existing studies are mixed with regards to evidence of the efficacy of internet-based interventions, they show promise in terms of both effectiveness, and acceptability, and further research into this area may establish the most effective ways in which online interventions for carers can be utilised.

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Conflicts of Interest

The authors of this paper have no conflicts of interest to declare.
Multimedia Appendix 1

Summary of studies – carers of individuals with psychiatric disorders

Multimedia Appendix 2

Summary of studies – carers of individuals who have survived a stroke

Multimedia Appendix 3

Summary of studies – carers of individuals with dementia; studies with a control group

Multimedia Appendix 4

Summary of studies – carers of individuals with dementia; studies without a control group

Multimedia Appendix 5

Summary of studies – carers of individuals with traumatic brain injury (TBI)
References


23. Glynn SM, Randolph ET, Garrick T, & Lui A. A proof of concept trial of an online psychoeducational program for relatives of both veterans and civilians living with schizophrenia. Psychiatr Rehabil J; 2010 Spring;33(4):278-87. PMID:20374986


25. Stjernswärd S, & Hansson L. Effectiveness and Usability of a Web-Based Mindfulness Intervention for Families Living with Mental Illness. Mindfulness (N Y); 2017;8(3):751-64. PMID:28515801


36. Torp S, Hanson E, Hauge S, Ulstein I, & Magnusson L. A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway. Health Soc Care Community; 2008 Jan;16(1):75-85. PMID:18181817


53. Wade SL, Stancin T, Kirkwood M, & Brown TM. Counselor-assisted problem solving (CAPS) improves behavioral outcomes in older adolescents with complicated mild to severe TBI. J Head Trauma Rehabil; 2014 May-Jun;29(3):198-207. PMID:23640543


64. Pagán-Ortiz ME, Cortés DE, Rudloff N, Weitzman P, Levkoff S. Use of an online community to provide support to caregivers of people with dementia. J Gerontol Soc Work; 2014 Oct;57(6-7):694-709. PMID:24689359
