## **Title Page**

Title: a systematic review of remotely delivered interventions to support wellbeing amongst caregivers of adults with acquired brain injuries

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Word count: 4936 (including abstract)

#### Abstract

Background: There is a need for improved access to evidence-based interventions supporting the wellbeing of caregivers of adults with acquired brain injury (ABI). Remotely delivered interventions could address this need. Objectives: The present systematic review sought to collate studies evaluating remotely delivered interventions designed to improve the wellbeing of caregivers of adults with an ABI, to summarise findings and to comment on the quality of this research. Methods: Systematic searches were conducted up until December, 2023. Study characteristics, populations, interventions and outcomes were outlined, and papers were appraised on methodological quality. The review was pre-registered (deducted to ensure blinding). Results: Eleven studies meeting inclusion criteria were identified. Methodological quality was generally low to adequate. Most studies evaluated an intervention for caregivers of people with stroke, with a variety of types of interventions trialled. The majority of studies reported non-significant findings on wellbeing outcomes when compared to control conditions. Conclusions: There is limited evidence supporting a remotely delivered intervention to improve wellbeing outcomes for ABI caregivers. Specific recommendations are provided, including the development of a core set of outcomes and replication of findings over time, which can improve research into the development and evaluation of remote interventions for this population.

Keywords: caregiving; carer support; ABI; brain injury; stroke; remote delivery; telehealth; mHealth

#### Introduction

Acquired Brain Injury (ABI) refers to an injury or illness resulting in damage to the brain, which occurred after birth, including Traumatic Brain Injury (TBI), strokes, brain tumours, infectious diseases or hypoxic injuries. ABI can lead to significant impairment in functioning, and in many cases lifelong disability with the person requiring support with activities of daily living (Denham et al., 2022; Jackson et al., 2009).

Supporting a loved one through their brain injury rehabilitation process and beyond can be rewarding, and caregiving can be a valued role in someone's life (MacKenzie & Greenwood, 2012; Pierce et al., 2007). Notwithstanding, research has also found that psychological distress, burden and reduced quality of life is common among caregivers of adults with ABI and that these difficulties often persist over time (Chung et al., 2021; Cumming et al., 2012; Denham et al., 2022; Sterckx et al., 2013). Prevalence of depression and anxiety is higher in ABI caregivers compared to the general population (Loh et al., 2017). The caring role is often time consuming with disruptions in areas such as employment and social life being common (Ilse et al., 2008; Lou et al., 2017). Greenwood (2010) and colleagues found that caregivers often felt unable to leave the care-recipient due to concerns for their safety. More time spent caring has also been associated with higher levels of caregiver stress suggesting that those with the least time on their hands to engage with services might be the ones needing it the most (Smith et al., 2014). As the informal caregiver provides a vital system of support for people with ABI following discharge from hospital, their own wellbeing is paramount for a sustainable rehabilitation (Cicerone et al., 2011; Pucciarelli et al., 2017; Turner et al., 2010). Unfortunately, emotional support and sufficient information are two of the most commonly reported unmet needs of the caregiver following discharge from hospital (Chen et al., 2021; Murray et al., 2006).

From a service perspective, insufficient funding, a lack of resources and clinicians without the required training are all potential reasons why this support is not being offered routinely (Sin et al., 2018). Services tend to focus on the person with the ABI, and the psychological needs of caregivers are given less priority (Bulsara & Fynn, 2006; Greenwood

et al., 2011). External factors can also hinder access and leave caregivers unable to attend services face-to-face. During the COVID-19 pandemic, services and social networks were at times completely inaccessible to caregivers (Beal, Pelser & Coates, 2023; Gallagher & Wetherell, 2020). Likewise, large distances to specialist ABI services means that this support is not always accessible in person for rural communities.

Whilst the need for supportive interventions to improve psychological wellbeing for caregivers of people with ABI is well documented, barriers are to be addressed to improve access to services. Remote delivery of interventions for ABI caregivers has the potential to achieve this and increase access to services. Previous reviews have focused on specific modes of delivery and populations.

Rietdijk and colleagues (2012) provide a systematic review on telehealth programs for family members of children and adults with TBI. Only one included study had a sample of caregivers of adult TBI survivors. This particular study by Brown and collegues (1999) evaluated a telephone-delivered intervention, using a non-randomised pre-post design, and reported reductions on measures of caregiver burden and psychological distress. Aldehaim and colleagues (2016) reviewed five studies on internet-based interventions for stroke carers. Only two studies were published papers using validated wellbeing outcomes, out of which one trial reported significant improvement in their sample on a measure of depression. Suntai, Laha-Walsh and Albright (2021) evaluated twelve remote interventions on stress in TBI caregivers, six of which involved adult care-recipients and carers. Mixed findings were described on the effectiveness to reduce stress.

Together, these reviews have suggested some benefits to caregivers. However, most studies in above reviews describe interventions designed for caregivers of children and young people with TBI, and are evaluated on a wide range of outcomes. Less is known regarding the benefits of remote delivery for caregivers of adults with any type of ABI, and specifically for psychological wellbeing as outcome. Moreover, looking closer at the interventions in previous reviews, many involve face-to-face elements mixed with remote elements, such as the study by Brown and colleagues (1999) in which the first group session is taking place in person. In the context of geographical barriers, or during extraordinary circumstances such as the COVID-19 pandemic, it is not always feasible for services or charities to deliver aspects of an intervention in person.

### The Present Review

The aim of the present review was to collate studies that evaluate a completely remotely delivered intervention designed to improve the psychological wellbeing of caregivers of adults with ABI. We wanted to describe the participants, interventions, and outcome measures of these studies, and to systematically evaluate their findings and methodological quality. In addition to providing a synthesis of this research, we aimed to provide specific suggestions of future directions in order to benefit the field. The literature on remote interventions tends to be divided into specific terminologies based on technologies or method of delivery such as telehealth, mHealth or web-based approaches. For the present review, however, a pragmatic stance was adopted to identify any type of nonpharmacological supportive or therapeutic intervention, as long as it is delivered completely remotely and designed to improve the wellbeing of caregivers of people with any type of ABI.

The systematic review question was: What are the outcomes, and quality, of studies targeted at improving psychological wellbeing of informal caregivers of adults with acquired brain injury using remotely delivered interventions?

#### **Methods**

#### **Procedures**

The protocol was pre-registered, prior to searching the databases (details deducted for blinding). The procedures of the present review were guided by the PRISMA systematic review guidance (Moher et al., 2009). Embase, MEDLINE, PsychInfo, Psych Articles, NeuroBITE (previously PsychBITE) and one grey literature database (opengrey.eu) were searched up until December, 2023. Searches were limited to English language; Boolean search terms were applied when possible and duplicates were removed as necessary. Four steps of search terms were created including variations of: type of ABI (stroke or subarachnoid\* or brain haemorrhage or brain injur\* or traumatic brain injur\* or TBI or ABI or acquired brain injur\* or encephalitis or meningitis or brain tumo\* or hypox\* or anox\*); remote delivery (distance or remote\* or home\* or self-help or tele\* or web\* or internet or video\* or biblio\*); intervention (intervention or therapy or program\* or support or information or training or management); and caregiver (caregiv\* or carer\* or partner or significant other). Each step was first searched individually and subsequently combined with 'AND' commands to generate the final search. This search strategy was adapted to fit the additional databases. Reference lists of identified studies were hand searched for further relevant studies.

#### **Eligibility**

As recommended in the PRISMA guidance, eligibility criteria were developed from considering Population, Intervention, Control, Outcome and Study design (PICOS). Records were included if the study evaluated a remotely delivered intervention designed to directly

improve the wellbeing of adults providing informal care to an adult with an ABI. All modes of delivery were of interest, and 'delivered remotely' was defined strictly as a programme being delivered without any face-to-face contact with the participant (i.e. the caregiver), and only assessments were allowed to be carried out in person as research activity. Records had to be randomised controlled studies (RCTs) using validated instruments measuring caregiver wellbeing. Any type of study control was included. Wellbeing was defined as, for example, psychological distress (e.g. depression, anxiety, stress), burden, quality of life and satisfaction with life. Secondary outcomes of interest were measures relating to the caregiver role such as mastery and satisfaction. Records were excluded if the sample included professional caregivers or care-recipients with degenerative neurological conditions (e.g. dementia). Records were also excluded if the article described a medical or pharmaceutical intervention, or if the paper had not undergone a peer-review process.

#### Search Process and Data Extraction

Figure 1 illustrates each stage of the search process. After duplicates were removed, the first author screened the titles, and abstracts were examined if required. The full text was accessed for each record selected from the screening and matched against eligibility criteria. The second author independently reviewed 25% of the full texts selected from the initial screening, and any disagreement was resolved through discussion. Data were extracted from each article by the first author including study design, characteristics of the sample, details regarding the intervention, outcomes and theoretical underpinning of the intervention. Effect sizes were transformed to Cohen's d. Data accessible in the records were used to calculate effects whilst authors were contacted for missing data.

### Methodological Quality

The quality of methodology and risk of bias was assessed using the Physiotherapy Evidence Database-Partitioned (PEDroP) scale, which has established reliability (Maher et al., 2003; NeuroBITE, 2020; Tooth et al., 2005; Verhagen et al., 1998). The scale has been used in systematic reviews of caregiver interventions and in the wider neurorehabilitation literature (Ownsworth & Haslam, 2016; Rietdijk et al., 2012).

Item 1 on the PEDroP relates to external validity. Item 1 is not accounted for in the total score. The following 10 criteria (item 2-11) are all evaluating aspects of internal validity. The first author rated all articles on methodological quality and the second author rated a randomly selected 25% of the studies independently. A substantial inter-rater agreement was observed (k = .71, p < .001) (Landis & Koch, 1977). Discrepancies were resolved through discussion and, when available, scoring was also confirmed by data from the NeuroBITE database. The power of reviewed studies was assessed, specifically if powercalculations were undertaken a-priori to estimate required sample sizes.

# Synthesis of findings

Due to the small sample of heterogenous studies identified, a narrative synthesis of the results is provided to summarise findings.

Results

Search Process

Figure 1 describes the search and selection process and the results of each stage. The

most common reasons for exclusion upon full-text inspection were that a study lacked

caregiver wellbeing outcomes. The search process resulted in a total number of 11 studies.

<Figure 1 here: PRISMA flow chart>

**Study Characteristics** 

Studies were published between 2003 and 2021 and originated from the United States

(n = 10) or Iran (n = 1). Sample sizes ranged from 35 to 254 (M = 110.4, SD = 70.3). Studies

compared a treatment condition with controls using two or three arm designs. Most designs

compared active treatment to written information or treatment as usual (TAU). In studies

where TAU acted as control condition, this was described as standard medical follow-ups for

the care-recipient. Written information consisted of a leaflet or a website containing

information about the ABI. Additional controls included telephone calls where a clinician

provided active listening (Bakas et al., 2015; Bakas et al., 2009; LeLaurin et al, 2021).

< Table 1 here: Summary of study and intervention characteristics>

Methodological Quality

The evaluation of methodological quality is detailed in Table 2. The PEDroP scale

has a score range between 0 and 10, with 10 representing excellent methodological standard.

The assessment of the reviewed sample yielded PEDroP scores ranging from 4 to 8 (M = 5.6,

SD = 1.2). In summary, the methodological quality was generally low to acceptable.

Attrition rates were high in most studies. As visible in Table 2, and in the right column in Table 1, only four studies had a total sample attrition rate below 15%. Attrition rates for intervention groups ranged from 1.2% to 44.4%. Only six out of eleven controlled studies employed intention-to-treat analysis. In fact, three studies had drop-out rates above 15% as well as lacking intention-to-treat analysis (Bakas et al., 2009; Hartke & King, 2003; Pierce et al., 2009). No study received scores for blinding of subjects or therapists; this type of blinding is not possible to achieve in a behavioural treatment study.

In addition to the PEDroP ratings, another methodological shortcoming was a lack of power. Only two studies provided a-priori power calculations that was adhered to in order to recruit a large enough sample for sufficient power (Bakas et al., 2015; Pierce et al., 2009).

< Table 2 here: Appraisal of methodological quality>

### Participant Characteristics

The studies selected for this review involved 1215 caregivers of which the majority (77%) were female (range = 57% - 100%). The mean caregiver age in the reviewed studies ranged from 49 (Goudarzian et al., 2018) to 69 (Hartke & King, 2003). All but two samples had a majority of spouses or partners. For the two additional studies the relationship was more broadly defined as being a family member (Goudarzian et al., 2018; McLaughlin et al., 2013). In studies providing data on care-recipients characteristics, these involved a total of 841 individuals of which the majority were male (62%), and samples ranged from 34.7% to 100% in terms of male gender of the care-recipients (Bakas et al., 2009, 2015; Bishop et al., 2014; McLaughlin et al., 2013; Milbury et al., 2020; Pierce et al., 2009; Powell et al., 2016; Smith et al., 2012). Mean sample age of care-recipients ranged from 42 (Powell et al., 2016) to 70 (Bishop et al., 2014). Most studies recruited caregivers of stroke survivors.

#### Interventions

Table 1 highlights that most interventions were delivered in an individual format to either the caregiver or to a dyad of caregiver and care-recipient. One study evaluated a group-based intervention (Hartke & King, 2003), and two studies described interventions using both group- and individual-based aspects of their package (Pierce et al., 2009; Smith et al., 2012). Telephone delivery was most common, whilst other delivery methods included video calls or online delivery.

All but one of the eleven interventions were delivered within twelve months of discharge from hospital. The exemption was the intervention in Hartke and King (2003) which was offered to caregivers during inpatient rehabilitation. Most interventions involved interaction with a clinician. Interventions were most often delivered by a nurse, and other professions included counsellors, social workers or various disciplines from a multidisciplinary team. The two interventions without any form of interaction were provided via a website.

Seven interventions were developed based on specific theoretical frameworks (Bakas et al., 2009, 2015; Bishop et al., 2014; Hartke & King, 2003; LeLaurin et al., 2021; Milbury et al., 2020; Pierce et al., 2009; Powell et al., 2016; Smith et al., 2012). The most common model was the stress-process model, which emphasises the importance of the caregiver's subjective experience of stressors and available psychosocial resources (Bakas et al., 2009, 2015; Hartke & King, 2003; Smith et al., 2012).

The most common component of interventions was psychoeducation, either on its own or in combination with other modules. Psychoeducation involved the provision of normalising information and coping strategies for emotional difficulties associated with being a caregiver. Four interventions involved stress-management modules. Three studies described interventions that used a problem-solving approach based on problem-solving therapy (Nezu

et al., 2013). One study evaluated a therapeutic intervention (Milbury et al., 2020), which consisted of a mindfulness-based intervention via online video delivery. Many interventions involved components targeting more practical aspects of caregiving, such as skill-building, information provision about the particular ABI, and didactic nursing instructions.

### **Outcomes**

Table 3 shows the outcomes of each study. Across the reviewed studies (N = 11), a total of 26 different psychometric instruments were used to measure the efficacy of interventions on caregiver wellbeing constructs. Further details regarding outcome measures, results and effect sizes are provided in Table 3. Effect sizes are Cohen's d, where small, medium and large corresponds to effect sizes over 0.20, 0.50 and 0.80, respectively (Cohen, 1988).

#### Psychological Distress

Depression was the most common outcome, explored in nine studies of which one reported significant improvement compared to control. Smith and colleagues (2012) evaluated an intervention delivered online to dyads utilising a mixture of group and individual formats and targeting both emotional and practical aspects of caregiving. The sample size was relatively small (N = 32) and the treatment effect had a medium, approaching large, effect size (d = -0.79) at post-treatment, which was maintained at follow-up one month later. Bakas and colleagues (2015) did not find a significant between-group difference when a telephone-based skill-building intervention was compared to attention-only control in a large sample (N = 254) of stroke caregivers. However, when analysing only a subgroup of participants with higher symptoms of depression at baseline (i.e. PHQ-9  $\geq$  5) the authors found a significant difference in depression scores between the treatment condition (n = 58) and control (n = 66) at post-treatment.

Anxiety was investigated in one study. Goudarzian and collegues (2018) found significant reductions on the Beck's Anxiety Inventory within the treatment group (d = -0.77), which represented a significant difference to TAU at post-treatment in favour of the intervention (d = -0.57). No follow-up was done and so it is not clear if this effect was maintained.

One study investigated distress as a general outcome. Powell and colleagues (2016) found a significant reduction in distress for caregivers who took part in a telephone-delivered intervention (n = 77), when compared to participants who received TAU as control (n = 76). No follow-up was conducted.

## Quality of Life (QoL)

Three studies explored caregiver-specific QoL, which was also conceptualised as *life changes* (Bakas et al., 2009; Bakas et al., 2015; Powel et al., 2016). All three studies measured QoL using the 15-item Bakas Caregiving Outcomes Scale (BCOS) (Bakas et al., 2006). No significant group differences to control conditions were observed at the end of the interventions or at follow-ups. The two studies that evaluated their intervention on satisfaction with life more broadly used the Satisfaction With Life Scale (McLaughlin et al. 2013, Pierce et al., 2009). No significant improvements were reported on satisfaction of life. *Burden and Stress* 

Two studies explored caregiver burden, with mixed findings. LeLaurin and colleagues (2021) did not observe any significant differences to control. In contrast, Hartke and King (2003) evaluated a telephone-based group intervention for spouses of stroke survivors in an acute rehabilitation setting and found this beneficial for subjective burden. Participants attended eight weekly teleconference sessions consisting of primarily psychoeducation. The authors found no significant effect at the end of the treatment, but did observe a significant treatment effect with a small effect size (d = -0.36) when compared to controls at follow-up.

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On stress as an outcome, Hartke and King (2003) found no significant differences compared

to control.

Secondary Outcomes

Bishop and colleagues (2014) reported significantly larger improvements in family

functioning and perceived criticism of the caregiver in their intervention group compared to

control at post-treatment. The intervention consisted of structured problem-solving and

psychoeducation and was delivered to dyads via the telephone. Bakas et al. (2009) found

changes on measures of optimism and threat appraisal in favour of the intervention at post-

treatment maintained at follow-up. No significant benefits were reported for loneliness

(Hartke & King, 2003), self-esteem (Smith et al., 2012) mindfulness, compassion or intimacy

(Milbury et al., 2020).

In addition to wellbeing outcomes, several studies investigated concepts relating to

the caregiver situation, and which could have an indirect impact on an individual's wellbeing.

Hartke and King (2003) found that caregivers reported a greater sense of competence,

compared to controls. The improvement was only seen on follow-up and the effect size was

small, approaching medium (d = 0.28). Mastery and social support were investigated in two

papers, but no significant changes were reported.

<Table 3 here: summary of outcomes>

#### Discussion

The aim of the present review was to collate studies that evaluate a completely remotely delivered intervention designed to improve the psychological wellbeing of caregivers of adults with ABI. Eleven studies were identified from the search process. These studies evaluated interventions delivered over the telephone, online, via videoconferencing and written material. Most interventions were offered within the first year following the ABI with a focus on psychoeducation. Depression was the most common outcome. We found limited evidence for the efficacy of remote delivery of interventions aimed at improving wellbeing outcomes for this population. Our findings are less supportive compared to reviews of similar populations (e.g. Aldehaim et al., 2016; Rietdijk et al., 2012; Suntai et al., 2021).

Suntai and colleagues (2021) report that most reviewed studies in their sample concluded that remote interventions are effective. Their sample consisted of studies evaluating interventions for caregivers of both children and adults with TBI. However, it was only studies evaluating caregivers of children that found benefit from a remote intervention, whilst studies with adult care-recipient samples found interventions not to be effective. Similarly, Rietdijk and colleagues (2012) report positive findings but the review includes only one study (out of 13) on caregivers of adults, which was a pre-post design.

It is possible that there are additional challenges in the context of being a caregiver for an adult which impact on the effectiveness of interventions. For example, post-injury role changes are considered more problematic for spouses compared to parents. The caregiver role can often involve aspects that resemble parenting, and spouses are required to suddenly transition into a completely new role (D'Ippolito et al., 2018). Caregivers of adults may require a different approach compared to parents of children with ABI.

The present review focused on psychological wellbeing as an outcome, rather than a general sense of benefit to people with ABI and their carers. This more specific aim could

contribute to our conclusions differing to previous reviews as it appears that psychological wellbeing is not consistently improved by the identified interventions.

A lack of differences to control conditions was particularly obvious for depression as an outcome, mainly due to this being the most common outcome studied. This finding is in line with previous reviews on remotely delivered interventions for caregivers of people with conditions other than ABI (Corry et al., 2019). In our sample, several studies reported low baseline depression scores (e.g. Bakas et al., 2015; Milbury et al., 2020; Pierce et al., 2009). In fact, the only study in the present review that reported a significant between-group difference on depression used a cut-off score of 5 on the PHQ-9 as an inclusion criterion for participation (Smith et al., 2012). Similarly, Bakas and colleagues (2015) only found a significant difference between intervention and control when they analysed a sub-group of participants with higher depression scores at baseline. Low baseline scores could have contributed to the lack of significant reductions on depression measures that was seen in the reviewed sample of studies.

### Methodological Quality

The overall methodological quality was low to adequate and findings must be interpreted with caution. Attrition rates in most of the reviewed studies were higher than the acceptable rate specified in the PEDroP appraisal tool. Average attrition reported for inperson cognitive therapy has been estimated to a similar rate as in the studies in the present review, suggesting this is not an unique issue to remote delivery (Fernandez et al., 2015).

Sample sizes varied greatly across studies and many trials lacked sufficient power for between-group analyses. There was a tendency to attribute small sample sizes to the fact that the study intended to pilot or assess feasibility of an intervention. The reviewed studies produced a large amount of non-significant findings, and low power to detect effects could be one possible factor. Finally, five out of eleven studies were found to have variations in

baseline scores between treatment and control group, which is another methodological flaw which requires consideration when interpreting any positive findings.

## Considerations for Future

The current literature, identified in this review, does not provide sufficient evidence to produce specific recommendations to clinicians in terms of what type of remote intervention improves wellbeing amongst caregivers of adults with ABI. The findings suggest caution when adapting already existing interventions into remote delivery, and careful planning and ongoing evaluation is recommended when developing and implementing new interventions.

The above-mentioned finding that several studies reported low baseline depression scores whilst also not finding a significant change in depression, compared to controls, raises the question whether these caregivers required intervention for depression. Services interested in offering remote support to caregivers may need to develop eligibility criteria to ensure interventions are appropriately targeted. Likewise, there could be benefits from incorporating experiences and needs discovered via qualitative methodology to inform future interventions (e.g. Greenwood et al., 2010; Lond & Williamson, 2018). For example, Lond and Williamson discovered that acceptance played a key role in adjustment and wellbeing of their sample of caregivers.

Across studies, interventions were evaluated on a large number of outcomes. This heterogeneity makes it difficult to make direct comparisons between studies in terms of efficacy. Future work should consider agreement and implementation of a core set of outcomes that can facilitate evaluation of interventions and integration of findings into practice. Outcome measures relating to psychological wellbeing are recommended due to this being an unmet need in this population. Outcomes such as depression, anxiety, quality of life and satisfaction with life can be measured using validated and well-established psychometric instruments translated into multiple languages.

Repeated evaluations of interventions across time and samples could also benefit the field. For example, Bakas et al (2015) found contrasting findings in the second evaluation of a telephone-based programme using a design with larger sample size and more rigorous methodology.

The majority of studies identified evaluated an intervention for caregivers of stroke survivors. There is a remaining gap in our knowledge with regards to remote interventions for caregivers of people with additional brain injuries that come under the ABI terminology (Boele et al., 2019; Piil et al., 2016). Caregivers of other aetiologies may respond differently to interventions due to variables such as age of carer, care-recipient or level of burden. Alternatively, evaluation of a generic model of caregiver intervention across various conditions could be considered.

#### Limitations of the Present Review

The search process was carried out manually by the lead author and there is a risk that existing records were missed and therefore not represented in this review. The selection process and the rating of methodological quality was carried out by the lead author and the second author which introduces a degree of subjectivity.

It was decided from the outset that only outcomes relating to the caregiver would be included. Caregivers and care-recipients often co-exist in dyads, and one could argue that a change on a care-recipient outcome would impact on the wellbeing of the caregiver. This link is not represented here and might limit the results of this review.

Effect sizes were transformed to Cohen's d for all effects in order to ease interpretation and data accessible in the records were used to calculate these whilst authors were contacted for missing data. Insufficient information (i.e. correlation data between preand post-treatment) to estimate effect sizes for the three articles reporting significant withingroup changes led to the decision to omit this data rather than risk presenting inaccurate

effects (Lakens, 2013). Attempts were made to retrieve this information from other sources, but these were not successful. Consequently, within-group changes and their effects are not presented.

### Summary of Recommendations

To summarise, the present review can offer the following recommendations and suggested directions for future research into remotely delivered interventions for caregivers of adults with ABI:

- 1) Recruit sufficient sample sizes, from a-priori power calculations, to reduce the risk of type II errors (i.e. false negatives) and sample biases.
- 2) Provide sufficient data in the results section or in supplementary documentation to make necessary calculations of both between- and within-group effect sizes. This would include data for means and standard deviations for baseline and post-intervention, and correlation data between pre- and post-intervention (i.e. test-retest reliability of the measure).
- 3) Consider eligibility criteria in services to ensure interventions target the intended outcomes.
- 4) Review, and/or conduct, qualitative/mixed methodological research to inform intervention development and implementation.
- 5) Consider introducing a core set of outcomes, which would benefit future evaluations and implementation research.
- 6) Replicate findings across time, and adapt previous intervention research into remotely delivered support.
- 7) Include caregivers of people with ABIs other than stroke and TBI, or consider a generic model of caregiver support.

### Conclusion

This review found limited evidence for the efficacy of interventions that are delivered remotely to improve the wellbeing of ABI caregivers. The need for further research is highlighted together with specific recommendations which we hope will benefit the field.

Albeit limited clinical benefits reported, we believe this is an area that can improve access to holistic neurorehabilitation in the future.

# Disclosure of Interest

The authors report no conflict of interest.

# Ethical standards

Not applicable.

# Declaration of funding

This research received no specific grant from any funding agency, commercial or not-forprofit sectors.

# Data availability statement

All available data are presented in the article or found in reviewed articles.

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Table 1 Summary of study and intervention characteristics

Study/Country	Design/Ctrl	Sample size	ABI	Interventio n target	Format and components of intervention	Number of contacts and length of int	Mode of delivery	Delivered by	Attrition*
Bakas et al. 2015 USA	RCT Ctrl: Attention (8 calls/active listening + written information)	N = 254	Stroke	Caregiver	Individual format Psychoeducation/Skill-building/Stress mgmt	8 weekly calls + 1 booster call	Written material + telephone	Nurse	Int: 8.1% Tot: 8.2% ITT: Yes
Bakas et al. 2009 USA	RCT Ctrl: Attention (8 calls/active listening + written information)	<i>N</i> = 50	Stroke	Caregiver	Individual format Psychoeducation/Skill-building/Stress mgmt	8 weekly calls	Written material + telephone	Nurse	Int: 19.2% Tot: 20% ITT: No
Bishop et al. 2014 USA	RCT Ctrl: TAU	<i>N</i> = 49	Stroke	Dyad	Individual format Psychoeducation/Problem-solving	13 calls to caregiver and 13 calls to care recipient over 22 weeks	Written material + telephone	Various	Int: not reported Tot: 38.8% ITT: Yes
Goudarzian et al. 2018 Iran	RCT Ctrl: TAU	<i>N</i> = 154	Stroke	Caregiver	Individual format Information/Telenursing	32 calls over 12 weeks	Telephon e	Nurse	Int: 1.2% Tot: 1.2% ITT: No
Hartke and King 2003 USA	RCT Ctrl: Written information	<i>N</i> = 124	Stroke	Caregiver	Group format Psychoeducational	8 weekly sessions	Telephon e	Various	Int: 36.8% Tot: 29% ITT: No
LeLaurin et al. 2021 USA	RCT Ctrl: Attention (active listening) VS TAU	<i>N</i> = 53	Stroke	Caregiver	Individual Psychoeducation/Problem-solving	4 weekly sessions VS 8 weekly sessions	Telephon e	Nurse	Int: 7.7% Tot: 3.8% ITT: Yes

McLaughlin et al. 2013 USA	RCT Ctrl: Written information	N = 201	ТВІ	Caregiver	Individual format Psychoeducation/advocacy/skill- building/Stress mgmt	No contact Minimum 30 minutes use over 10 days	Website	-	Int: 14% tot: 10% ITT: Yes
Milbury et al. 2020 USA	RCT Ctrl: TAU	<i>N</i> = 35	Brain tumour	Dyad	Individual format Therapeutic/Mindfulness	4 weekly sessions	Video call	Counsellor	Int:44.4% Tot: 37.1% ITT: Yes
Pierce et al. 2009 USA	RCT Ctrl: TAU	<i>N</i> = 103	Stroke	Caregiver	Individual and group format Psychoeducation/Information/Social support	No contact Average use of 1-2h per week over 1 year	Website + email	Nurse + MDT	Int: 29.4% Tot: 29.1% ITT: No
Powell et al. 2016 USA	RCT Ctrl: TAU	<i>N</i> = 153	TBI	Caregiver	Individual format Psychoeducation/Information/Problem- solving	10 calls over 20 weeks	Written material + telephone	Social worker	Int: 23.4% Tot: 18.3% ITT: Yes
Smith et al. 2012 USA	RCT Ctrl: Written information	<i>N</i> = 38	Stroke	Dyad	Individual and group format Psychoeducation/information/stress mgmt/Skill-building	2 weekly chat sessions over 11 weeks	Website + email + online chat	Nurse	Int: 36.8% Tot: 23.7% ITT: Yes

<sup>1-1 =</sup> individual-based intervention, ABI = Acquired Brain Injury, Ctrl = Control, Int = Intervention group, ITT = Intention-To-Treat, *N* = total sample size of study, RCT = Randomised Controlled Trial, TAU = Treatment As Usual, TBI = Traumatic Brain Injury; Tot = total attrition rate

<sup>\* =</sup> Attrition rates were calculated from participants dropping out between being allocated and post-treatment assessment

 Table 2 Methodological quality of controlled trials

	1. Eligibility criteria was specified	2. Allocation was random	3. Allocation was concealed	4. Intervention groups were similar at baseline	5. There was blinding of all subjects	6. There was blinding of all therapists	7. There was blinding of all assessors <sup>a</sup>	8. Outcomes obtained from > 85% of the sample <sup>b, d</sup>	9. Subjects received condition/ intention- to-treat analysis <sup>c</sup>	10. Reported between- group statistical comparisons <sup>d</sup>	Point measures and variability <sup>d</sup>	Total (Item 2-11)
Bakas et al. 2015	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	8/10
Bakas et al. 2009	N	Y	Y	Y	N	N	Y	N	N	Y	Y	6/10
Bishop et al. 2014	Y	Y	N	Y	N	N	Y	N	Y	Y	Y	6/10
Goudarzian et al. 2018	Y	Y	N	Y	N	N	N	Y	N	Y	Y	5/10
Hartke and King 2003	Y	Y	Y	N	N	N	N	N	N	Y	Y	4/10
LeLaurin et al. 2021	Y	Y	Y	N	N	N	Y	Y	Y	N	Y	6/10
McLaughlin et al. 2013	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	7/10
Milbury et al. 2020	Y	Y	Y	N	N	N	N	N	Y	Y	N	4/10
Pierce et al. 2009	Y	Y	N	Y	N	N	N	N	N	Y	Y	4/10
Powell et al. 2016	Y	Y	Y	N	N	N	Y	N	Y	Y	Y	6/10
Smith et al. 2012	Y	Y	Y	N	N	N	Y	N	Y	Y	Y	6/10

Note: <sup>a</sup> who measured at least one key outcome; <sup>b</sup> of participants allocated to groups; <sup>c</sup> for subjects of which outcome measures were available, and for at least one key outcome; <sup>d</sup> For at least one key outcome

 Table 3 Summary of efficacy on caregiver wellbeing outcomes

Study and outcomes (measure)	Between-group differences at post-treatment (Effect size)*	Between-group differences at FU (Effect size)*
Bakas et al. 2015		
Depression (PHQ-9)	ns	ns
Life changes (BCOS)	ns	ns
Bakas et al. 2009		
Depression (PHQ-9)	ns	ns
General health (SF-36GH)	ns	ns
Threat appraisal (ACS)	In favour of intervention at post-treatment ( $d = -0.85$ )	In favour of intervention at FU ( $d = -0.77$ )
Life changes (BCOS)	ns	ns
Difficulty with tasks (OCBS)	ns	ns
Optimism (LOT-R)	In favour of intervention at post-treatment ( $d = 0.87$ )	In favour of intervention at FU ( $d = 0.89$ )
Bishop et al. 2014		
Depression (GDS)	ns	No FU
Family functioning (FAD)	In favour of intervention at post-treatment ( $d = 0.81$ )	No FU
Criticism (PCS)	In favour of intervention at post-treatment ( $d = -0.95$ )	No FU
Goudarzian et al. 2018		
Depression (BDI)	ns	No FU
Anxiety (BAI)	In favour of intervention at post-treatment ( $d = -0.57$ )	No FU
Hartke and King 2003		
Depression (CES-D)	ns	ns
Burden (BI)	ns	In favour of intervention at FU ( $d = -0.36$ )
Stress (PPI)	ns	ns
Loneliness (UCLA)	ns	ns
Competence (CCS)	ns	In favour of intervention at FU ( $d = 0.28$ )
LeLaurin et al. 2021		
Depression (CES-D)	ns	ns
Burden (ZBI)	ns	ns
McLaughlin et al. 2013		
Satisfaction with life (SWLS)	ns	ns
Milbury et al. 2020		
Depression (CES-D)	ns	ns
Mindfulness (MAAS)	ns	ns
Compassion (SCS)	ns	ns
Intimacy (PAIRI)	ns	ns
Pierce et al. 2009		

Depression (CES-D)	ns	ns
Satisfaction with life (SWLS)	ns	ns
Powell et al. 2016		
Distress (BSI-18)	In favour of intervention at post-treatment ( $d = -0.41$ )	No FU
Quality of life (BCOS)	ns	No FU
Mastery (MCAS)	ns	No FU
Smith et al. 2012		
Depression (CES-D)	In favour of intervention at post-treatment ( $d = -0.79$ )	In favour of intervention at FU ( $d = -0.52$ )
Self-esteem (SES)	ns	ns
Mastery (MS)	ns	ns
Social Support (MOS)	ns	ns

Abbreviations: ACS = Appraisal of Caregiving Threat Subscale, BAI = Beck Anxiety Inventory, BCOS = Bakas Caregiving Outcomes Scale, BDI = Beck Depression Inventory, BI = The Burden Interview, BSI-18 = Brief Symptom Inventory, CCS = The Caregiver Competence Scale, CES-D = The Center for Epidemiologic Studies—Depression Scale, FAD = Family Assessment Device, FU = Follow-up, GDS = The 13-item Geriatric Depression Scale, LOT-R = The Revised Life Orientation Test, MAAS = Mindful Attention Awareness Scale, MCAS = Modified Caregiver Appraisal Scale, MOS = MOS social support survey, MS = Mastery Scale, OCBS = Oberst Caregiving Burden Scale Difficulty Subscale, PAIRI = Personal Assessment of Intimacy in Relationships Inventory, PCS = Perceived Criticism Scale, PHQ – 9 = The Patient Health Questionnaire, PPI = The Pressing Problem Index, SCS = Self-Compassion Scale, SES = Self-Esteem Scale, SF-36GH = The SF-36 Health Survey General Health Subscale, SWLS = The Satisfaction with Life Scale, UCLA = The UCLA Loneliness Scale, ZBI = Zarit Burden Interview-Short Form \* Negative sign on effect size indicates that reduced score equals improvement on measure

**Figure 1.** PRISMA flow diagram of the search and selection process **Alt text for Figure 1:** A visual representation of the selection process from the initial search resulting in 5707 records to the final 11 selected papers, including the steps; identification, screening and eligibility assessment.

