Family-oriented interventions for adults with acquired brain injury and their families: a scoping review

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Abstract

Objective

This scoping review sought to describe the literature about the different types of interventions to support families of patients with acquired brain injuries and their outcomes.

Introduction

Acquired brain injuries are among the leading causes of disability in adults worldwide and have physical, cognitive or/and behavioral consequences not only for the patient, but also for the family. Several support interventions have been proposed in different contexts at different phases of recovery with various levels of evidence, yet no synthesis is available to date.

Inclusion criteria

We included studies that focused on family members of patients suffering from ABI. The concept under review included any type of intervention or action oriented to support families of patients with ABI, in any care setting. We included all published qualitative and quantitative designs, including those in the grey literature.

Methods

A three-step search strategy was performed. Searches were conducted in eight major databases, Medline, PubMed, Embase, CINAHL, PsycINFO, Cochrane, JBI EBP, Web of Science in April 2017, and seven databases for unpublished studies in November 2017. This review was limited to studies published in English and French since January 2007. Additional studies were searched amongst reference lists of all included articles.

Results

We included 89 studies, 19 secondary studies (systematic reviews n=13, other type of reviews n=6) and 70 primary studies (experimental studies n=20, quasi-experimental studies n=33, other designs n=17). Even if heterogeneity was found in the characteristics of the 64 selected interventions, emotional support and education were highlighted as main core components for family-oriented interventions. Mental health and burden were the two most frequent outcomes found in this scoping review. Interventions targeted families and patients together in 56% of the cases or families alone.

Conclusion

This scoping review provides an actual state of the current evidence available for families of patients with acquired brain injuries. An extended and heterogeneous literature was found, showing the growing interest for considering ABI as a family issue in these last years. However, the overall level of evidence

found, indicates that more research is still needed to determine key components to intervene within this specific population.

Keywords

Brain injury, caregivers, family, family oriented-intervention, nursing, scoping review

Background

Acquired brain injuries (ABI) are one of the leading causes of disability in adults worldwide.[1] ABI include all traumatic and non-traumatic brain injuries acquired after birth that are not related to congenital or degenerative diseases.[1] The main forms of traumatic brain injuries (TBI) are haematoma, concussion and cerebral contusion: the severity of injury ranges from altered mental status to total loss of consciousness .[1] Traumatic injuries are mostly due to road accidents, falls, gunshot-related wounds or sport accidents.[1] Non-traumatic injuries, such as stroke, tumors and aneurysms are mainly due to vascular malformations, brain infections, or anoxia.[1]

The effects of ABI, whether they are traumatic-related or not, on motor and cognitive functions can be significant and result in major changes in lives of the patients and their families.[2] Depending on the severity of the injury and the spread of the lesion, ABI can temporarily or permanently impact on physical health (i.e. quadriplegia, paraplegia or hemi-syndrome), cognitive functions (i.e. attention deficit disorder, memory loss or concentration troubles), behaviour (i.e. managing emotion, stress or problem-solving disabilities), and personality.[2] In the acute phase, care provided by multidisciplinary teams aims to maintain neurological and homeostatic stability, and to preserve vital functions. Some institutions offer opportunities for patients with ABI to receive intensive inpatient rehabilitation care; the goal being to maintain or improve function related to activities of daily living (ADL) in order to improve social and working reinsertion, as well as quality of life.[3]

In the chronic phase, many patients present difficulties for finding work, mainly due to communication impairments and inabilities to use everyday life technology (i.e. answering the phone or turning on a computer) and to perform ADL.[4] Inability to work impacts negatively on the economic situation of the family as well as on their social standing.[5,6]

Although cognitive impairments can be more difficult to diagnose, when compared to physical injuries, they often have devastating consequences.[7] Due to the sudden nature and unpredictability of ABI, patients and their families find themselves in situations that they are unable to handle.[8] The consequences of ABI on family members may affect their dynamics and functioning, resulting in need for roles and responsibilities' readjustment.[9–11] A systematic review including 22 original articles, reported the impact of support for patients with TBI and their families.[12] The results showed that nurses' interventions should include three dimensions of support: the informational, the emotional and the practical dimension, since family members need information, education, emotional support, support to adjust psychological and social aspects, and even administrative support. The authors recommended that all these aspects should be considered in order to promote coping strategies for families.

If those needs are not met, family members may experience poor emotional and physical health, such as decreased well-being, increased burden, poor family functioning and lower quality of life. Well-being refers to life satisfaction, emotional functioning and caregivers burden.[13] In the chronic phase of the injury, relatives of people with ABI report dissatisfaction with their life as a whole and a high level of burden.[13,14] Burden is characterized by the individuals feelings of being overwhelmed, forced to change their life plans or be confined.[15] It is multidimensional and can be exacerbated by remote access to care,

limited patient's social and family functioning as well as social support. It may vary according to the degree of severity of functional disorder and the patients' autonomy in ADL.[16–19] Family members of patients with ABI often report poor family functioning, which does not improve with time.[20–22]

Supporting families of patients with ABI may include various intervention modalities, such as support groups for family members of patients requiring intensive care, communication interventions, and/or flexible visiting hours.[23] To date a few studies have explored interventions targeted at the patient and their family for the population of patients with ABI. A review of the literature published in 2007 included 31 experimental and quasi-experimental studies with family interventions targeted to carers of patients with brain injury (four studies) and with other chronic conditions (27 studies).[24] Interventions included educational information, support group, tele-rehabilitation, case management, therapy, peer support, or a combination of multiple components. Results highlighted a lack of methodological rigour of the selected studies, an important heterogeneity within the population of interest as well as in the nature of the family interventions, and no benefit in any of the specific interventions supporting families of patients with ABI. Additionally, a systematic review, including 18 studies, reported positive effects of family counselling on psychosocial adjustment in stroke patients' caregivers.[25] However, to the best of our knowledge, no study determining the effect of intervention for families of patients with ABI in general (and not specific to a particular condition, such as stroke or TBI) has been reported. To date, there is no clear understanding of what defines family interventions, especially regarding the core components constituting the interventions as well as the characteristics and the expected outcomes for interventions with patients with ABI and their families. Thus, given the nature, the extent, and the heterogeneity of the current literature, it is relevant to map out the different characteristics (type, delivery mode, frequency, duration, provider, expected outcomes) of family-oriented interventions designed for all types of patients with ABI and their families.This step is essential prior implementation of any support intervention during the course of injury and recovery. This scoping review was undertaken to assist us in clarifying the core components of family interventions tested in the population with ABI at the different stages of care from the acute to the chronic phase of injury. It was also to inform us on the relevant outcome measures used in the studies. Ultimately, the results of this scoping review help us to evaluate the necessity for performing a systematic review on efficacy of interventions.

Review Questions

The aim of this scoping review was to examine the range and nature of the family-oriented interventions that have been developed and/or tested for people with ABI and their families in all settings by answering the two following questions:

- What are the aims and characteristics (type, delivery mode and duration, provider) of the family-oriented interventions available for people with ABI and their families?
- What types of outcomes have been reported in the literature when testing or implementing family-oriented interventions?

Inclusion Criteria

Types of Participants

The review considered studies that included participants who were:

a) Adult patients with ABI, including TBI, stroke, anoxia or tumour, from any gender, culture and ethnicity admitted to a healthcare facility.

This definition excluded patients suffering from dementia, Alzheimer, or congenital diseases, since their clinical development and disease characteristics are rather different. This definition also excluded the paediatric population, since the family context and the interventions for the whole family are different too.

b) Family members: All members of family of patient with acquired brain injury including spouse, husband, partner, children, parents, siblings that were caregivers or non-caregivers as defined by a group of people linked by deep emotional attachment and a sense of belonging to groups, where everyone identifies as family members.[26]

Concept

The concept for this scoping review referred to all types of interventions or actions designed for families of patients with ABI. This definition included, but was not limited to:

Any type of intervention or action designed to improve outcomes for the patient and for its family members. Nature of intervention/action could be education, emotional or information, focusing on either family/caregivers only, or family/caregivers and patient. Whether the intervention was developed with a systemic or a family-centred care framework was documented. Interventions focusing on patient only, were excluded in congruence with family's vision of care.

Context

To have a broad picture, this scoping review considered studies conducted in all care settings (e.g. intensive care, acute care, inpatient, inpatient rehabilitation, outpatient rehabilitation, chronic care, homecare, and community setting) in any country.

Study Types

This review considered all study designs, including randomized controlled trials, non-randomized controlled trials, before and after studies, interrupted time-series studies, analytical observational studies including prospective and retrospective cohort studies, case-control studies, analytical cross-sectional studies, qualitative and mixed methods studies.

This review considered also descriptive observational study designs, including case series, individual case reports and descriptive cross-sectional studies, meta-analysis and grey literature for inclusion. Published study protocols, text, opinion and policy documents were excluded.

Methods

149 The JBI methodology for scoping reviews was used to conduct this scoping review.[27] The a-priori
150 protocol was accepted and is available on JBI Database of Systematic Reviews and Implementation
151 Reports. [28]

152 **Search Strategy**

153 The search strategy aimed to find both published and unpublished studies. A three-step search
154 strategy was developed and conduct in conjunction with a librarian. The first step was an initial limited
155 search of Medline and CINAHL. It was followed by an analysis of the text words contained in the title
156 and abstract of the retrieved papers, and of the index terms used to describe the articles. The second
157 step was a search using all identified keywords and index terms across the following databases:
158 Medline, PubMed (search limited to references not indexed in Medline), CINAHL, Cochrane, Joanna
159 Briggs Institute EBP Database, Embase, PsycINFO, Web of science Core Collection. The search for
160 unpublished studies included OpenGrey, ProQuest Dissertations & Theses, DART Europe E-theses
161 Portal, BASE (Bielefeld Academic Search Engine), WHO International Clinical Trials Registry Platform
162 and Clinicaltrials.gov. Studies published in English and in French were included. The period considered
163 was from 2007 to the date of the searches (April 2017 for the search in the bibliographic databases and
164 November 2017 for the search of the unpublished studies). The rapid evolution of technology for
165 interventions (i.e.: electronic devices, web-based intervention) and reanimation process (i.e. medical
166 progress, rehabilitation access) justified this timeframe. Full search strategies are provided in Appendix
167 1.

168 During the third step, we searched for additional studies amongst all identified reports and
169 articles' reference lists.

170 **Study Selection**

171 Following the search, all identified citations were collated and uploaded into a citation
172 management system (Endnote X7), and duplicates removed. Titles and abstracts were screened by two
173 independent reviewers (VdG and LR) for assessment against the inclusion and exclusion criteria for the
174 review using the web-based citation management system Rayyan QCRI.[29] Divergences between the
175 two reviewers were resolved with a third independent reviewer (ASR). A similar process was used for
176 full-text inclusion in the review. We reported the decisions for exclusion in accordance with the preferred
177 reporting items for systematic reviews and meta-analyses (PRISMA) statement.[30] Reasons for exclusion
178 are documented in Figure 1.
179

180 **Data extraction**

181 A charting table was developed for the protocol as recommended by the JBI methodology for
182 scoping review to record the key information of the selected studies.[27] The relevant data extracted
183 included author(s), year of publication, origin/country of origin (where the study was published or
184 conducted), aims/purpose, design, study population and sample size (if applicable), type of intervention,

duration of the intervention, provider of the intervention, type of outcomes, key findings related to the scoping review questions.

Review results

Description of studies

The search from the eight databases of published studies yielded 4930 citations. After the removal of duplicates, 2787 citations were screened for inclusion. The six databases of unpublished references identified 587 additional citations. After removal of duplicates, we considered 422 citations, resulting in a total of 3209 citations screened on the basis of the titles and abstracts. From this process, we excluded 2879 studies and included 89, and the latter were 19 secondary studies (systematic reviews n=13, other type of reviews n=6), and 70 primary studies (experimental studies n=20, quasi-experimental studies n=33, other designs n=17). Figure 1 shows details of selection process, reasons for exclusion and study selection.

[Insert Figure 1]

Aims and characteristics of the primary selected studies

Table 1 presents a summary of the aims and type of each intervention, as well as the country, the population, the provider, the duration, the delivery mode, the outcomes, the target population and the key findings of the intervention. Many different types of interventions were found in the included primary studies. Interventions recorded are made up of 1 to 7 core components. A total of 64 interventions was recorded; 5 interventions were found in several publications.[31–42]

Interventions took place in fifteen countries, mostly in the U.S.A. (n=30)[31–38,43–64] and in Europe (n=22).[39,40,65–84] A majority of studies (n=35) included families and patients after stroke[8,31,32,34,35,41,42,48,51,54,57,58,65,67–69,72,75–80,83–93], 14 studies included patients with TBI[39,45–47,49,52,56,60,64,70,85,94–96], nine included patients with ABI[37,38,53,59,71,73,74,97,98], eight interventions included persons with undefined brain injuries (BI)[36,40,43,50,61–63,99] and four included patients with other neurological conditions.[44,66,81,82]

[Insert Table 1]

Type of intervention

Figure 2 presents the number and the nature of core components used in each intervention. The 64 interventions included in this scoping review presented 24 different core components. Table 2 summarizes the different core components recorded. The most frequent (n=33) core components were emotional support[8,31–33,36–40,43,45–48,50,57,65,67,73–77,79,86,87,89,91,93,95,98], which included support from professionals and peer support, education (n=32) and specifically active information[8,31–33,36–38,41,42,44,45,48,49,53,57,59,60,65–67,69,75,78,81,86,89–93,98,100], and to a lesser extent (n=16) coping skills[31–38,43,48,50,59,73,79,95,99]. Information was a core component used in 12 studies[31–33,48,55,66,77,78,86,95,101], and problem-solving skills was a core component in 11 studies.[31–35,43,45,49,67,68,70,95]

[Insert Table 2] [Insert Figure 2]

Duration, frequency, timing of delivery and delivery mode of included interventions

The structure of each intervention is presented in Appendix 2 and a synthesis of these results is provided in Table 3.

[Insert Table 3]

Duration. The majority of the interventions were conducted for a period of less than three months (n=30)[8,31–42,46,53–55,58,66,67,69,71,72,75,77,79,82–84,86,92,94–96,99,102], 12 interventions lasted between 3-6 months[43,47,50,52,60,61,88–91,93,101] and 11 lasted six to 12 months[48,49,51,56,57,64,70,74,76,81,97]. Six interventions lasted between one and two years.[44,45,65,68,78,98]

Frequency. Most interventions had irregular frequencies (n=25)[34,35,39,41,42,44–46,48,50,51,54,55,57,58,61,63,64,66,68,70,73,74,86,90,96,101], 18 interventions took place weekly or bi-weekly[8,31–33,43,67,71,72,75,77,79,82–84,88,92,94,95,98,99], 13 took place monthly to bi-monthly[47,49,52,56,65,76,78,80,89,91,93,97], and three had one session.[40,53,69]

Timing of delivery. More than 50% of the interventions were designed for an application during the chronic phase[8,36–38,44,46–50,52,54,56–58,61,64,67,68,70–72,75,78,82–84,88,89,91,92,94,95,97–100,102]. Almost 20% of interventions took place during the transition phase of discharge from hospital setting.[31–35,41,42,45,51,55,60,63,85,86,90,93] Nine interventions were tested during the rehabilitation phase.[50,53,66,73,76,77,79,81,96] Five interventions started during or in the acute phase.[39,40,65,69,101]

Delivery mode. Interventions were largely delivered in the form of meetings (n=33)[8,36–40,43,50,52,64,66–69,71–73,75–77,79–83,83,84,88,91,94–96,100], such as group meeting, peer support group, face-to-face interviews or workshops. Seventeen studies combined different forms of delivery such as meetings and phone calls[34,35,41,42,44,45,47,70,86,89,90,93,99,101] or use of technologies and group support meetings.[48,55,78] Six interventions used technologies-based interventions (website, electronic devices, and online applications) only.[46,53,54,57,60,63] Other ways of delivery were phone calls (n=3)[31,33,49,51] including a helpline or regular phone calls.

Provider of intervention

Providers of the interventions included different profiles as detailed in Table 1. Nurses (registered nurses, advanced practice nurses, specialized nurses) provided 27% of all interventions autonomously.[31–35,41,42,53,54,58,63,65–67,80,81,91,93] Therapists including general therapists, family therapists, psychiatrists, psychologists and behavioral therapists delivered 21% of interventions.[36,38,55,56,64,71,76,77,82,83,85,94–98] Mixed teams (including different members of multidisciplinary team, researchers or therapists) provided almost 18% of the interventions.[45,47,48,50,51,57,69,72,78,84,88,90,92,100] Facilitators including researchers, staff members of association, interventionists and community volunteers delivered 14% of the interventions.[8,43,44,60,61,70,75,78,79,101] In some interventions, family members were active actors for the intervention delivery, as for instance in peer support groups, but

they were always coached by professionals to do it in an appropriate way and to find resources if needed be.[45,66,72,88,91]

Type of outcomes

A full description of the outcomes is presented in Table 1. The main outcomes found and their frequency of occurrence are presented in Figure 3. Out of the 70 selected primary studies, 39 (56%) measured patient and family/caregivers-related outcomes, and 31 (44%) families/caregivers only. When patient and family/caregivers-related outcomes are measured together, the most frequent outcome (n=24) was in the mental health category (i.e.: anxiety, depression, prostration, perceived criticism, stress and distress).[31,33–35,39,44,48,54–56,58,61,65,66,68,70–73,76,83,84,86,98,100] Burden of care was the second most frequent outcome relating to 16 interventions[34,38,47–49,54–56,66,73,85,86,90,92,98,100]. General health was assessed in relation to 13 interventions[33,39,40,44,47–49,56,57,70,75,88,89], satisfaction in 12 interventions[36,37,41,42,44,46,50,55,57,64,69,79,81,88,96], and implementation process-related outcomes in 11 interventions.[8,39,47,58,76,77,79,80,88,93,101] Eleven interventions targeted cognitive aspects, such as knowledge or problem solving.[37,44,46,53,60,65,70,71,75,78,86] It should be noted here that one intervention also included nurse-related outcomes (nurse's attitudes).[81]

Specifically, most of patient-related outcomes (n=9) were mental health[48,54,58,72,73,83,84,86,98] or physical aspects (n=9), including functional status and physical disabilities.[34,39,48,54,55,57,66,88,92] Communication skills were assessed in five interventions.[50,60,75,77,82] Knowledge (including information and education) was evaluated in four interventions.[60,75,77,86] Other patient-related outcomes included measures of ADL[41,42,81,88], quality of life[45,58,84,86], wellbeing[45,75,83,89], participation in social life[45,81,89,98] and self-efficacy.[43,58,86] Patient's self-reported family functioning was assessed in two interventions.[51,97]

Family members or caregiver-related outcomes were mainly burden (n=17)[34,38,47–49,54–56,66,73,85,86,90,92,98–100] and level of depression (n=14).[31,33–35,39,44,48,55,58,66,68,70,76,86] Wellbeing was assessed in seven interventions[45,47,57,70,75,83,89], as well as quality of life,[39,40,45,58,76,84,93] knowledge (i.e. about disease, consequences, prevention) was assessed in six,[46,60,65,77,78,86] and family needs also.[32,34,36,38,41,42] Preparedness for caregiving was assessed in five studies,[34,35,41,42,63]as well as assessment of communication skills.[50,75,77,82,94] Family functioning was measured in four studies,[51,91,97,100] coping[48,58,61] as well as participation in social life each in three studies.[45,81,89]

[Insert Figure 3]

Aims and characteristics of the secondary selected studies

Table 4 proposes a full description of the 19 secondary studies included. Most of them (n=14) focused on patients with a specific condition, such as stroke[25,103–115]. Two reviews examined interventions for populations with ABI[24,116], one for patients with TBI[117] and one for the population with any type of BI.[118] Ten studies focused on caregiver-related outcomes only[103,104,108,111,112,115–119] and nine focused on patient and family/caregiver-related outcomes.[24,25,106,107,109,110,113,114,120] One review considered an intervention for caregivers of people with chronic condition, including stroke.[119] Globally, in the results and in the discussion of the majority of studies more research on the topic was

recommended, as to date, no intervention for families of patients with ABI has demonstrated a strong level of evidence.

[Insert Table 4]

Discussion

The results of this scoping review are extended and heterogeneous. Development and testing of an intervention specific to the population with ABI and their family has been of great interest, especially in the United States and in Europe. No high level of evidence indicating significant positive results for patients and their families have been described so far, but several studies showed promising results. Almost 20% of studies included in the present review are secondary studies that summarized not only the primary studies recorded here, but also older literature. In the last decades, the interest for family and caregivers' health and wellbeing has been growing for patients with ABI, thus recognizing that ABI is a family issue.

Review question 1: What are the aims and characteristics (type, delivery mode, duration and provider) of the family-oriented interventions available for people with ABI and their families?

The target population of the included studies were mostly stroke patients and their families. TBI patients and their families represented 20% of the total population included. Patients with ABI were represented in a limited number of interventions. This shows the interventions described in the literature were specifically tailored to a specific type of injury, rather than to any patient with an ABI, even if they demonstrated to have similar needs in terms of recovery and family support.[6,10–12] The choice of focusing on a specific condition might be due to facilitated access to a specific population, such as stroke patients and to the need to conduct research in a controlled environment and minimize bias. However, this approach limits research transfer into clinical practice,[121] which caters for the population of all patients with ABI and their family, independently of the specific condition of the patient. This issue needs to be addressed in future research, because the literature already shows similarities in family needs and challenges between stroke and TBI patients, whose main injuries are defined within ABI.[5,10–12] For clinical healthcare teams, this is an important issue to consider, as they want to offer better care for this population and their families. As many studies recommended tailoring interventions for families, it is relevant to have stronger levels of evidence on key components of interventions for families of patients with ABI that could be adapted to every family specifically. Here we should also underline that 11% of interventions recruited families of people with BI, without a precise definition of BI being stated. A more specific definition of the targeted population could help clinicians and researchers to improve the quality of the studies performed and therefore increases the overall level of evidence in the literature about ABI knowledge.

The interventions main characteristics were heterogeneous in terms of type and aims, as well as in the delivery mode, duration and provider of the interventions. Most interventions had more than one core component. These interventions can be defined as complex interventions by nature, as they are mostly multicomponent interventions.[122] Nevertheless, interventions with only one core component

330 should also be considered complex, because they focused on behavioral changes, which is complex
331 per se. The two main core components, education and emotional support, were congruent with the
332 literature describing family needs of families of patients with ABI. Families often reported unmet needs
333 about information and emotional support, as well as they considered that they were two issues that
334 should be a priority for healthcare providers to consider.[123–127] Future research should be experimental
335 in design in order to grow the evidence about efficacy of these two core components and how they
336 should be combined.

337 The duration of interventions in the selected studies were also heterogeneous ranging from less
338 than three months to over one year in acute care, and until two years for interventions in community
339 settings. These differences in duration are related to the way of delivery, the frequency and the type of
340 providers. There are many ways to deliver the family-oriented interventions, depending on the aim of
341 intervention, the spread of the injury and the needs of the family members. In the acute phase, the
342 heterogeneity of interventions was more important than in the chronic phase, with irregular amounts of
343 session and frequency, but with similar ways of delivery (meetings and phone calls only). This difference
344 may be due to the uncertainty of the situation for patients and families. In order to better support families,
345 it may be indicated to follow the patient's own rhythm, instead of imposing frequent interventions that
346 cannot be respected in many cases (i.e.; clinical and logistical issues for patient, families and healthcare
347 providers). Regarding the interventions designed for the chronic phase, findings showed a trend in the
348 regularity of the sessions, but great difference in the number of sessions: duration ranged between six
349 hours[71,80] (weekly, bi-weekly, and bi-monthly) and less than 3 months (up to 240 hours of personal
350 therapy during 6 months to one year and spread across three different modules).[74] A more in depth
351 review about these characteristics should be investigated further in a feasibility study and cost-analysis
352 study.

353 Different profiles of providers have been recorded in this review. ABI can lead to serious
354 cognitive and physical impairments, which can lead to a chronic condition. The nature of impairments
355 following an ABI is so complex to deal with, that family members and patients meet a large variety of
356 different healthcare professionals (i.e. medical doctor, registred nurse, occupational therapist, speech
357 therapist, neuropsychologist, family therapist, volunteers of association); these results emphasized the
358 importance of interprofessional collaboration to take care and support patient and family members.
359 Thus, healthcare professionals should be informed of the best evidence to care about this population
360 and their families to work in complementary ways to ensure the continuity and coordination of care.[128,129]
361 This issue is a major challenge. It should be noticed that nurses represent the largest group of
362 intervention providers recorded in this review, highlighting the important role nurses play in caring,
363 supporting and preventing adverse issues for patients and families.

364 *Review question 2: What types of outcomes have been reported in the literature when testing or*
365 *implementing family-oriented interventions?*

366 Most of the interventions recorded here focused on patient and families/caregivers outcomes,
367 more than on caregivers outcomes only. These results are promising as it suggests a patient and family

368 centred-care approach in which the patient and family is considered as a unit of care. A wide range of
369 outcomes were evaluated, family-, caregiver- and patient-related outcomes. As a whole, the most
370 frequent outcomes evaluated were related to mental health and burden of caregiving. These results are
371 congruent with other results, as we already know the impact of taking care of a loved one.[16,18,19] One
372 result was surprising; despite the scope of this review being the inclusion of family-oriented
373 interventions, findings about family functioning assessment were evaluated in only four studies.[51,91,97,100]
374 To the best of our knowledge it is an important indicator when testing family interventions in health,[26] it
375 shows how family members interact with each other and what type of resource they have and do not
376 have, when trying to put coping strategies in place in dramatic situations, such as having a loved one
377 with ABI.

378 *Theoretical framework underpinning the included studies*

379 A few studies reported using a systemic or a family-centered care framework to support the
380 intervention being tested. Nevertheless, twenty four studies included patient and families as the focus
381 of the intervention[31,33–35,39,44,48,54–56,58,61,65,66,68,70–73,76,83,84,86,98,100] showing the growing interest in including
382 more than one person of the family. Some interventions are based on a systemic approach, but were
383 not specified as such (i.e.Multi Family Group Therapy). The lack of clarity about the theoretical
384 framework underpinning the development of the intervention prevented us from interpreting the results
385 with precision. Nevertheless, family interventions in the systemic approach are defined as invitation to
386 change for every members of the family and can be categorized following three main domains[26,102]: 1)
387 cognitive (which refer to understanding, capability, and enhanced coping), b) affective (emotional well-
388 being), 3) behavioral (interactions within and outside the family). Another domain, the coordination and
389 continuity of care, appeared in this review. Most of the core component interventions recorded in this
390 review (62%) referred to the cognitive domain (including, education, information, coping skills, problem-
391 solving skills, psychoeducation, communication, prevention and advocacy components). The second
392 most important domain was the affective domain with 24% of core component (i.e.: emotional support
393 core component and Multi Family Group intervention). Ten percent of the interventions included in this
394 review concerned the coordination and continuity of care, including coordination aspects, instrumental
395 support and health management. The less represented domain was the behavioral one with only 4% of
396 the core components recorded, including cognitive behavioral treatment and relaxation.

397 **Limitations**

398 The aim of this scoping review was to present the breadth of the existing literature about family-oriented
399 interventions for patients with ABI. As the results were heterogeneous, the results presented here could
400 only be descriptive in nature and present the range of evidence available on this topic. Population, key
401 components, countries and providers were heterogeneous and should be considered as such. Studies
402 recorded in this review ranged from 2007-2017 only, and were limited to English and French literature.
403 Inherent to the scoping review methodology, this review did not assess the quality of the studies
404 included, thus the effect of the interventions was not reported.

405 **Conclusion**

This scoping review provides an actual state of the current evidence available for families of patients with ABI. Due to heterogeneity, the results must be considered only as descriptive, but they showed promising orientation when developing and testing interventions for patients and families outcomes. Nevertheless, to date, the level of evidence is low and further good quality research is clearly needed to improve the quality of the literature available for the patients and families after ABI. The paradigm shift moving from caregivers to family as a whole need to be developed in further research to enhance coping and empowerment of the whole family, as well as family functioning. They need to be supported in better ways and recognized as real partners.

Conflicts of Interest

The authors declare no conflicts of interest.

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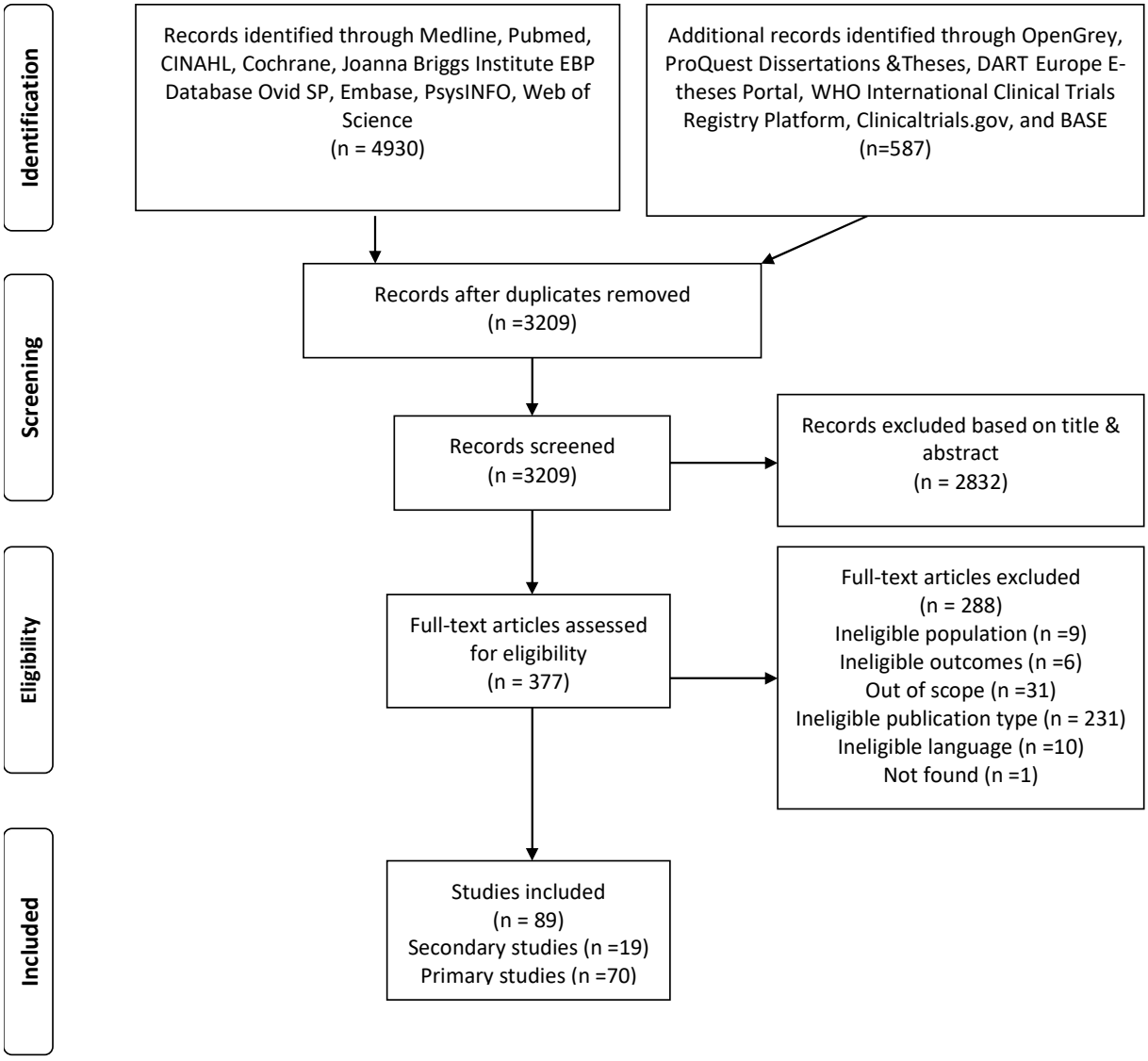
Figures

Figure 1: PRISMA Flowchart of studies selection and inclusion process



From: Moher *et al.*[30]

Figure 2: Type of core components, frequency of occurrence in the interventions included

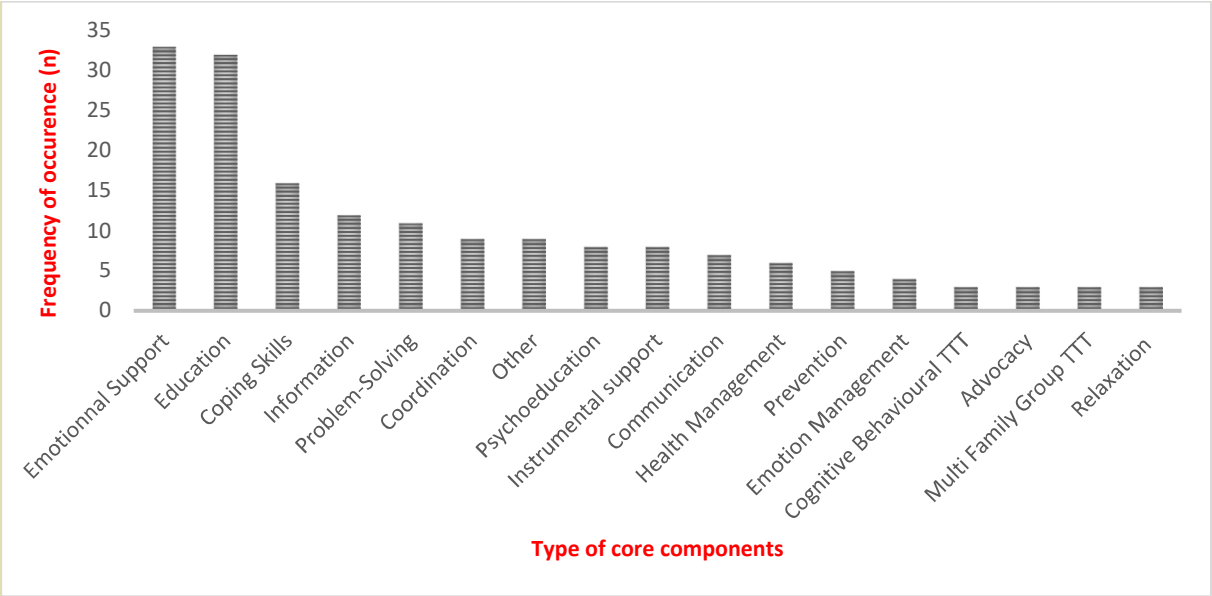


Figure 3: Main outcomes with frequency of occurrence in the interventions included

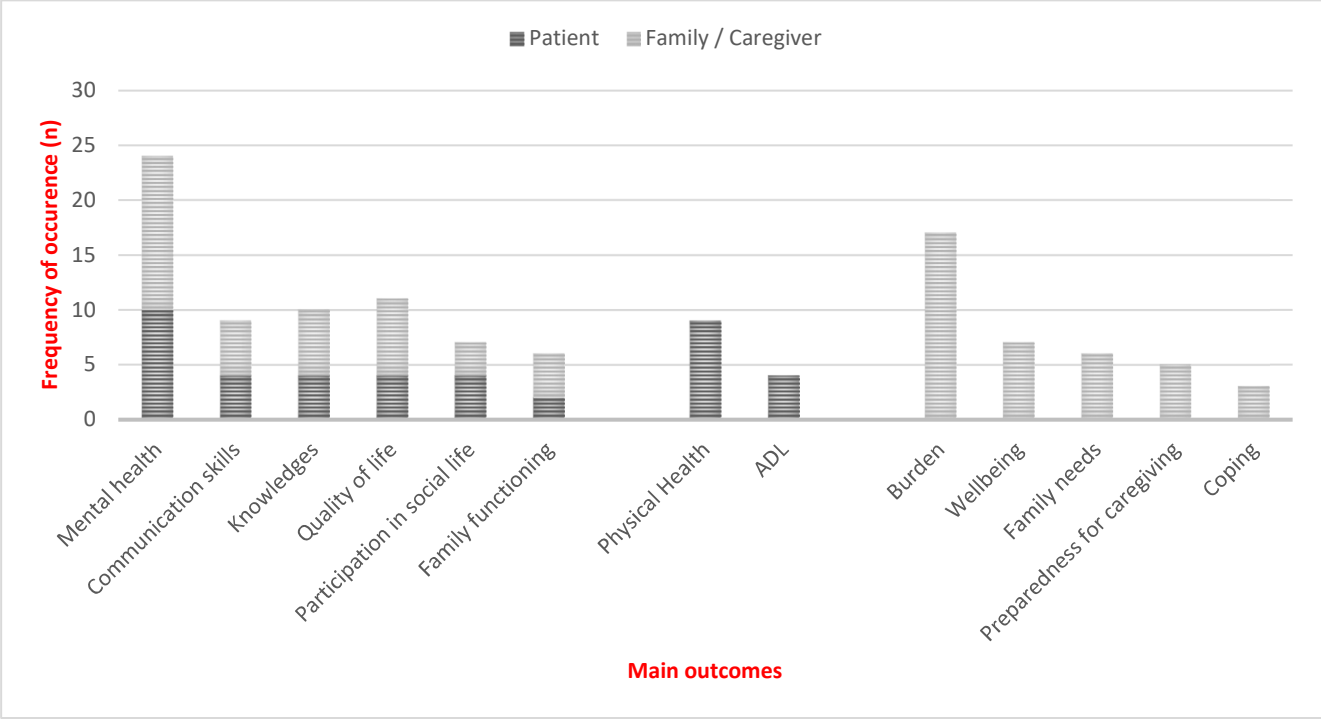


Table 1 Description of the selected primary studies by design

Author	Country	Design	Aim & Purpose	Pop. sample size	Type of ABI	Type of Intervention	Delivery mode & Duration	Providers	Types of outcomes		Significant findings
									Patient	Family member / Caregiver	
Backhaus *et al.*[43]	U.S.A	Exp.	To determine whether training in coping strategies will improve psychologic functioning and self-efficacy.	Dyads IG: 10 CG: 10	BI	Multicomponent	12 face to face sessions of 2 hours	Facilitator	Perceived self-efficacy	Emotional functioning	↑ Perceived self-efficacy immediately post treatment and maintained this over time.
Bakas *et al.*[33]	U.S.A	Exp.	To explore the efficacy of the TASK program in improving stroke caregiver outcomes.	Caregivers IG: 21 CG: 19	Stroke	Multicomponent	8 weeks program	RN	none	Optimism Task difficulty Threat appraisal Depressivon Life changes Health perceptions	↑ Optimism, task difficulty, and threat appraisal.
Bakas *et al.*[31]	U.S.A	Exp.	To evaluate efficacy of the Telephone Assessment and Skill-Building Kit (TASKII).	Caregivers IG: 123 CG: 131	Stroke	Multicomponent	8 weekly calls and a booster session 1 month later	RN	none	Depression Life changes, Unhealthy days	↓ Depressive symptoms, Unhealthy days (not sustained over the long term). ↑ Life changes,
Eames *et al.*[86]	Australia	Exp.	To evaluate the effects of an education package which utilized both strategies on the knowledge, health and psychosocial outcomes of stroke patients and carers.	Dyads IG: 60 CG: 59	Stroke	Multicomponent	Up to 3 face-to-face interviews pre- discharge, phone contact up to 3 times post discharge and helpline,	OT	Stroke knowledge's Self-efficacy Anxiety Depression Information Quality of life	Stroke knowledge's Self-efficacy Anxiety Depression Information Burden	↑Self-efficacy for accessing stroke information and satisfaction with information
Elliott *et al.* [44]	U.S.A	Exp.	To examine the effectiveness of an individualized problem-solving intervention provided to family caregivers of women living with severe disabilities.	Dyads IG: 38 CG: 43	Other	Single component	Monthly contact in month 1, 4, 8 and 12	Facilitator	none	Social Problem-Solving Depression scale Satisfaction with Life Measure of health complaints	↓ Depression over time. ↑ Problem solving over the year.
Franzen-Dahlin *et al.*[65]	Sweden	Exp.	To determine whether a nurse-led support and education programme for spouses of patients affected by stroke improved the psychological health of the spouses.	Caregivers IG: 46 CG: 45	Stroke	Multicomponent	6 group meetings monthly with a follow-up after 6 months	RN	none	Comprehensive Psychopathological Rating Scale Self-Affective for psychological health	No significant results Although high participation =↑psychological health
Hanks *et al.*[45]	U.S.A	Exp.	To examine the efficacy of a peer-mentoring program for persons with traumatic brain injury (TBI) and their significant others, and to determine the relationship of this mentoring program to 3 main outcomes	96 patients 62 caregivers	TBI	Multicomponent	Meet and/or talk via telephone weekly /1st month, biweekly /next 2 to 3 months, monthly for the remainder of the 1rst year.	Therapist, RN, and facilitator	Emotional wellbeing Quality of life Community integration	Emotional wellbeing Quality of life Community integration	↑behavioral control, good physical quality of life ↓chaos in the living environment, alcohol use, emotion-focused and avoidance coping
Hirsch *et al.*[66]	Germany	Exp.	To examine whether a training program for family caregivers of neurological patients has effects on the relatives' depression, prostration, and subjective burden.	Caregivers IG: 14 CG: 14	Neuro	Multicomponent	4 sessions	RN	Functional status	Depression Prostration Subjective burden	↓ Prostration scores over 3 measurement points in CG. ↓ Burden score ↑ Barthel indices (both groups).
Inci & Temel[67]	Turkey	Exp.	To determine the effect of a support program on the resilience of female family caregivers of stroke patients.	Caregivers IG: 34 CG: 36	Stroke	Multicomponent	5 sessions	RN	none	Resilience	↑Relative and friend support, Social support and Family-coping coherence.
McLaughlin *et al.*[46]	U.S.A	Exp.	To examine the efficacy of an interactive multimedia intervention that teaches advocacy skills to people caring for a family member with TBI.	Caregivers IG: 104 CG: 97	TBI	Multicomponent	multimedia	Website	none	Caregiver knowledge Skill application Behavioral intention Life satisfaction	↑ Application, knowledge, and attitudes immediately post intervention and at follow-up.
Moriarty *et al.*[47]	U.S.A	Exp.	To determine if the Veterans' In home Program is more effective than standard outpatient clinic care in improving family members' well-being and to assess its acceptability to family members.	63 dyads IG: 29 CG: 34	TBI	Multicomponent	6 home visits and 2 phone calls over a 3- to 4-month period.	OTs and facilitator	none	Well-being Caregiver burden Caregiver satisfaction Acceptability	↓ Depressive symptom scores, Burden Acceptance of the intervention was high.

Author	Country	Design	Aim & Purpose	Pop. sample size	Type of ABI	Type of Intervention	Delivery mode & Duration	Providers	Types of outcomes		Significant findings
									Patient	Family member / Caregiver	
Ostwald *et al.*[48]	U.S.A	Exp.	To compared 6- and 12-month outcomes of a home-based psychoeducational program to mailed information provided to 159 survivors of stroke and their spousal caregivers.	Dyads IG: 69 CG: 65 dyads	Stroke	Single component	6 month	RN, OT and PT	Health status Depression Stress Burden Coping Support, mutuality Functional status	Health status Depression Stress Burden Coping Support, mutuality	↓ Depression, stress ↑ Self-reported health and cognitive function (survivor) ↑ Self-reported health and coping (carer) ↓ Mutuality and social support (both)
Pfeiffer *et al.*[68]	Germany	Exp.	To examine the effectiveness of a problem-solving intervention for stroke caregivers who provided care for at least 6 months and who experienced significant strain in their role.	Caregivers IG: 60 CG: 62	Stroke	Single component	2 home visits and 18 phone calls over 3-months + 9-months maintenance	Therapist	none	Depressive symptoms Sense of competence	↓ Levels of depressive symptoms after 3 months and after 12 months.
Powell *et al.*[49]	U.S.A	Exp.	To determine if a telephone-based, individualized education and mentored problem-solving intervention would improve outcomes for caregivers.	Caregivers IG: 77 CG: 76	TBI	Multicomponent	10 calls maximum	Social Worker	none	Caregiving Outcomes Symptoms Functional status	↑ Active coping ↓ Emotional venting
Rivera *et al.*[70]	U.K.	Exp.	To test if a problem-solving training program would lower depression, health complaints, and burden, and increase well-being reported by community-residing family caregivers.	Caregivers IG: 33 CG (education only): 34	TBI	Multicomponent	4 in-home sessions and 8 telephone follow-up calls over one year	Facilitator	none	Depression Health complaints Well-being Social problem-solving abilities	↓ Depression, health complaints, and in dysfunctional problem-solving styles over time.
Perrin[85]	Colombia	Exp. *Study in process*	To improve TBI rehabilitation through stronger information caregiving.	Dyads IG: 110 CG: 108	TBI	Multicomponent	5 sessions one 6 weeks	Therapist	none	Burden	No results to date
Lloyd[71]	U.K.	Exp. (Thesis)	To investigate the feasibility of using an ACT intervention to reduce the psychological distress and psychological inflexibility of carers.	Caregivers IG: 8 CG: 10	ABI	Single component	3 x 2 hours sessions On 4 weeks	Therapist	none	Psychological distress, value-based behavior Flexibility of thinking	No statistically significant results
McMakin[83]	U.K.	Exp. (Thesis)	To investigated the feasibility and efficacy of an interactive group-based Positive Psychotherapy intervention for stroke survivors and carers. It aims to improve their psychological well-being.	8 survivors & 2 caregivers IG: 10 CG: 10	Stroke	Multicomponent	5 X 2 hours group session	Therapist	Psychological wellbeing Psychological distress	Psychological wellbeing Psychological distress	No statistically significant results
Stamatakis *et al.*[72]	U.K.	Exp. (Thesis)	To evaluate the efficacy of a community-based stroke peer support intervention for survivors and carers.	Dyads IG: 23 CG: 24	Stroke	Multicomponent	5-weeks program (1.5-2hours sessions weekly)	Facilitator Therapist	Psychological distress	Psychological distress	↓Psychological distress ↑Perceived social support / Quality of life
Ivey-Williams[84]	U.K.	Exp. (Thesis)	To examine the efficacy of a 4 sessions Acceptance and Commitment Therapy intervention for stroke survivors and carers.	Dyads IC: 31 CG: 38	Stroke	Multicomponent	4 sessions on 4 weeks 2 hours	Therapist Facilitator	Psychological distress Post-traumatic growth Quality of life	Psychological distress Post-traumatic growth Quality of life	No statistically significant results
Aguirrezabal *et al.*[69]	Spain	QE	Evaluate the effect of a post stroke information and carere training intervention in the rehabilitation hospital setting on patient and carers' satisfaction	IG: 76 patients / 73 carers CG: 74 patients / 85 carers	stroke	Single component	2 hours sessions after the first week	Interdisciplinary team	Satisfaction	Satisfaction	↑ levels of satisfaction (both)
Backhaus *et al.*[50]	U.S.A	QE	To examine the feasibility of providing a group intervention to individuals with brain injury and examine if improvements occur in relationship satisfaction and communication.	9 dyads	BI	Multicomponent	16 weeks	NP OT	Satisfaction Communication	Satisfaction Communication	↑satisfaction and Quality of relationship ↓negative communication
Bishop *et al.*[51]	U.S.A	QE	To test the efficacy of a telephone intervention, Family Intervention: Telephone Tracking, designed to assist stroke survivors and their primary caregivers during the first 6 months after stroke.	49 dyads	Stroke	Single component	weekly for 6 weeks, biweekly for the next 2 months, and then monthly for 2 months,	Therapist RN	Family functioning, General functioning, Health care utilization, Psychosocial functioning	Family functioning, General functioning, Health care utilization, Psychosocial functioning	↑Family functioning caregiver functioning. psychosocial outcomes ↓ Family criticism, health care utilization

Author	Country	Design	Aim & Purpose	Pop. sample size	Type of ABI	Type of Intervention	Delivery mode & Duration	Providers	Types of outcomes		Significant findings
									Patient	Family member / Caregiver	
Brown *et al.*[52]	U.S.A	QE	To test whether a curriculum-based advocacy-training program improves advocacy behavior when compared to a matched group engaged in self-directed advocacy activities.	IG: 104 CG: 111	TBI	Single component	4 x 6 hours session over 4 months	Association staff	Advocacy	Advocacy	↑ In advocacy message.
Cameron *et al.*[101]	Canada	QE	To examine feasibility of conducting a randomized controlled trial of the TIRSFSP and collect pilot data.	31 caregivers	Stroke	Multicomponent	From acute care to 6 month follow-up support by phone	Facilitator	none	Feasibility Acceptability	Feasible
Chang *et al.*[88]	South Corea	QE	To examine the effects of a family involvement and functional rehabilitation program in an adult day care center	19 dyads	Stroke	Multicomponent	12 weeks intervention	RN PT & CMP	Functional levels, AVQ Cost of health services	Satisfaction Health perception Cost of health services	↑ Functional levels, AVQ Health perception Satisfaction
Charles *et al.*[97]	Australia	QE	To explore multifamily group work with families with a parent with an acquired brain injury	6 families	ABI	Single component	12 sessions over 6 months	Therapist	Individual, couple and family functioning Emotional symptoms Index	Individual, couple and family functioning Emotional symptoms Index	↓Level of personal distress Positive participation
Egan *et al.*[89]	Canada	QE	To describe and evaluate a Community Stroke Navigation program	35 stroke survivors and 26 caregivers	Stroke	Multicomponent	1-8 x during 4 months phone calls between visits.	OT	Community reintegration well-being	Community reintegration well-being	↑in community reintegration among the stroke survivors
Fortune *et al.*[73]	Ireland	QE	To examine if a brief structured multicomponent group program for carers was effective in reducing carer distress, strain, and critical comments between carer and person with an AB.	Caregivers IG: 75 CG (waiting list): 38	ABI	Multicomponent	6 1/2-day core modules plus 3 elective modules	Team	Psychological distress Perceived criticism FIM	Caregiver strain Perceived criticism Psychological distress	↓Carers' perceptions of stress and strain ↓Perception of criticism ↓ at 3 months in levels of criticism expressed
Gerber & Gangaro[98]	Canada	QE	To describe and evaluate a new day program for persons living with an ABI, including persons exhibiting challenging behaviors.	61 dyads	ABI	Multicomponent	2 days per week	Therapist	Isolation Participation in community Social and leisure skills Goal attainment	Satisfaction Goal attainment Burden	↑ Community integration ↓ Family burden
Geurtsen *et al.*[74]	Netherland	QE	To examine the effects of a residential community reintegration program	41 caregivers	ABI	Multicomponent	44h per person	Multidisciplinary team	none	Emotional burden Psychological health family functioning	↑ Emotional burden Psychological health
Kim *et al.*[90]	Korea	QE	To develop effective intervention program that can reduce family caregiver burden.	Caregivers IG: 42 CG: 31	Stroke	Multicomponent	1 session in hospital 14 phone calls during 3 months.	Clinical team	none	Burden	↓Family caregivers' burden.
King *et al.*[34]	U.S.A	QE	To examine the efficacy and durability of a caregiver problem-solving intervention on caregivers and stroke survivors outcomes	15 caregivers	Stroke	Multicomponent	From acute rehabilitation and continued through 2 months after discharge.	RN	Motor / cognitive function	Depression Anxiety Perception of life Preparedness Burden Needs Healthy caregiving	↓Depression, anxiety, ↑preparedness, and survivor motor function
King *et al.*[35]	U.S.A	QE	To assess the efficacy of a caregiver problem-solving intervention on stroke caregiver physical and psychosocial adaptation compared and to assess the mediation effects of coping on outcomes.	255 caregivers	Stroke	Multicomponent	From acute rehabilitation and continued 3 months post discharge	RN	none	Depression Anxiety Preparedness Life changes Family functioning	↓Depression, ↑ Life change, health Improvements
Knapp *et al.*[53]	U.S.A	QE	To assess the potential benefit of virtual dialogues with experts	8 caregivers	ABI	Single component	1 session	RN	none	Knowledge	↑ Knowledge
Kreutzer *et al.*[36]	U.S.A	QE	To evaluate the benefits of the Brain Injury Family Intervention (BIFI) for families of persons with acquired brain injury and identify factors related to outcomes.	53 families	BI	Multicomponent	10 weeks 5x2h sessions	Therapist	none	Satisfaction Family Needs Service Obstacles	↑In met needs, greater satisfaction with services,
Kreutzer *et al.*[38]	U.S.A	QE	To examine the effectiveness of BIFI.	80 families	ABI	Multicomponent	5 X 2-hour sessions	Therapist	none	Family Needs Service Obstacles Burden	↑In met needs, greater satisfaction with services, ↓burden relative

Author	Country	Design	Aim & Purpose	Pop. sample size	Type of ABI	Type of Intervention	Delivery mode & Duration	Providers	Types of outcomes		Significant findings
									Patient	Family member / Caregiver	
Lutz *et al.*[54]	U.S.A	QE	To create and implement a stroke dialogue for an in-home messaging device tailored for veterans with stroke and their family caregivers.	9 Veterans 6 caregivers	Stroke	Dialogues for an in home-messaging device	14 days	RN	Physical impairment, Depressive symptoms, Fall prevalence	Burden	Intervention is feasible ↑security outcomes and education
Mackenzie *et al.*[75]	U.K.	QE	To examine the operational feasibility of and response to a new eight-session weekly group intervention program, Living with Dysarthria.	6 people 3 caregivers	Stroke	Multicomponent	8 sessions weekly	Facilitators	Communication Well-being, Knowledge Rating of goal	Communication Well-being, Knowledge Rating of goal	↑Intelligibility and knowledge of stroke and dysarthria. Program is feasible
Malini[91]	India	QE	To evaluate the impact of support group intervention on family system strengths of rural caregivers of stroke patients.	Caregivers IG: 120 CG: 120	Stroke	Multicomponent	meetings over a 3-month period	RN	none	Family system Strengths of rural caregivers of stroke patients	↑ Family system strengths of caregivers.
Marsden *et al.*[92]	Australia	QE	To explore whether a group program for community-dwelling chronic stroke survivors and their carers is feasible in rural settings;	25 patients & 17 caregivers	Stroke	Multicomponent	1x- week, seven-week group program.	PT, social worker, dietician, RN, speech pathologist, OT.	Health-related quality of life Functional performance	Health-related quality of life Functional performance Burden	This program is feasible and may improve outcomes
Mores *et al.*[8]	Canada	QE	To evaluate the content, format and resource materials of the FICSS program with 10–12 family caregivers of stroke survivors.	11 families	Stroke	Multicomponent	4x 2hours	Facilitators	none	Process	Caregivers valued the opportunity to share experiences and learn from others.
Norup *et al.*[40]	Denmark	QE	To investigated the effects of acute neuropsychological intervention for relatives.	Caregivers IG: 39 CG: 47	BI	Multicomponent	1–1.5 h sessions depending on the relatives	NP	none	Symptom Quality of life	↓ Anxiety scores from the acute to the sub-acute setting ↓ Role Emotional scores.
Oupra *et al.*[93]	Australia	QE	To develop and implement SELF for stroke survivors in Thailand and to evaluate its effect on family caregiver's strain and quality of life.	Dyads IG: 70 CG: 70	Stroke	Multicomponent	3 sessions over three months	RN	none	Strain Quality of Life	↓caregiver strain ↑ Quality of life.
Palmisano & Arco[99]	Australia	QE	To examine effects of in-home neurobehavioral interventions on the behavior of adults with brain injury, and on their spouses' burden of care.	3 dyads	BI	Single component	weekly 1-hour home visits or telephone calls	NP	Functional behavior	Burden	↑ Functional behavior
Perlick *et al.*[56]	U.S.A	QE	To evaluated the initial efficacy and feasibility of implementing multifamily group treatment for veterans with traumatic brain injury (TBI)	14 Dyads	TBI	Single component	9 months	Therapist	Interpersonal functioning	Empowerment Burden	↓Veterans anger ↑Social support and occupational activities ↓Burden ↑Empowerment
Perrin *et al.*[55]	U.S.A	QE	To develop and implement the Transition Assistance Program (TAP) for stroke caregivers.	61 dyads	Stroke	Single component	1 meeting prior to discharge. 4 videophone calls In weeks 1, 2, 4 and 6	Therapist	Functional status	Strain Depression Satisfaction	↓caregiver strain at the 3-month follow-up. ↓ depression ↑ functioning for VA
Pierce *et al.*[57]	U.S.A	QE	To test if carers of stroke survivors who participate in the Web-based intervention, Caring*Web[a], would have higher well-being than non-Web users.	Caregivers IG: 36 CG: 37	Stroke	Multicomponent	1 year	Health care team	Use of services Functional index	Well-being Satisfaction with life	↓in emergency department visits and hospital readmissions related to the health of survivors
Robinson-Smith *et al.*[58]	U.S.A	QE	To examine the impact of a psychoeducational intervention to expand coping skills and identify themes for focused nursing strategies to assist post stroke couples.	Dyads IG: 5 CG: 5	Stroke	Single component	6 sessions	RN	Dyadic coping Quality of life Depression Self-care self-efficacy	Dyadic coping Quality of life Depression	↑coping by oneself and quality of life; ↓depressive symptoms ↑in positive dyadic coping for group spouses.
Shyu *et al.*[41]	Taiwan	QE	To test the effectiveness of a discharge planning program for dyads of older stroke survivors and their family caregivers in Taiwan	Dyads IG: 72 CG: 86	Stroke	Multicomponent	4-5 times during hospitalization and 1 phone call within the first week	RN	ADL	Preparedness for Caregiving Discharge Needs Satisfaction	↑nurse evaluation and self-evaluation of preparation after the program than before, ↑satisfaction of discharge needs one month after discharge than before discharge.

Author	Country	Design	Aim & Purpose	Pop. sample size	Type of ABI	Type of Intervention	Delivery mode & Duration	Providers	Types of outcomes		Significant findings
									Patient	Family member / Caregiver	
Shyu *et al.*[42]	Taiwan	QE	To explore the long-term effects of a discharge-preparation program targeting Taiwanese family caregivers of older patients with stroke	Dyads IG: 72 CG: 86	Stroke	Multicomponent	4-5 times during hospitalization and 1 phone call within the first week	RN	ADL	Preparedness for Caregiving Discharge Needs Satisfaction	↑ Better quality of care during 12 months ↓ Service access
Togher *et al.*[94]	Australia	QE	To determine if treatment focused on improving the conversational skills of everyday communication partners resulted in improvements in perceived communicative ability	38 people	TBI	Single component	2.5 hours sessions weekly for 10 weeks	Therapist	none	Communication	↑conversational performance relative Maintained at 6 months post-training.
Wilz & Barzkova[76]	Germany	QE	To investigate the effectiveness of a cognitive behavioral group program for spouses of stroke patients.	Dyads IG: 38 CG: 51	Stroke	Single component	15 bi-monthly 2 h sessions.	Therapist	none	Depression Quality of Life.	Significant short-term changes in caregiving spouses' quality of life and with long-term changes in their quality of life and depression.
Bakas *et al.*[32]	U.S.A	Descriptive	To explore patterns of perceived needs and skill building during a stroke caregiver intervention programme.	123 caregivers	Stroke	Multicomponent	8 weeks program	RN	none	caregivers needs	Information about stroke is highest priority (Session 1) Managing survivor emotions and behaviors is highest priority (Sessions 2) Emotional and physical health needs comes later.
Blom Johansson *et al.*[77]	Sweden	Multiple case	To design and evaluate an early family-oriented intervention of persons with stroke-induced moderate to severe aphasia and their significant others in dyads.	3 dyads	Stroke	Multicomponent	6 weekly 45-minutes treat. sessions:	Therapist	Feasibility Acceptability, Emotional support and information, knowledge about aphasia, Communication	Feasibility Acceptability, Emotional support and information, knowledge about aphasia, Communication	↑ Knowledge and understanding of aphasia and related issues.
Damianakis *et al.*[95]	Canada	Descriptive	To explore the therapeutic benefits of an online support group for caregivers of young adult survivors of TBI and explore group process therapeutic mechanisms within a video conferencing support group environment.	10 caregivers	TBI	Multicomponent	10 weekly sessions	Therapist	none	none	Main themes are caregiver burden, stress, and difficulty managing and challenges of therapeutic intervention online.
Godwin *et al.*[59]	U.S.A	Descriptive	To outline the need for the integration of resilience tenets into rehabilitation techniques,	none	ABI	Multicomponent	none	none	none	none	Importance of integrating Resilience in rehabilitation
Hernandez *et al.*[60]	U.S.A	Case report	To describe the utilization of clinical Video Telehealth to enhance treatment, communication and education for caregivers.	1 veteran and 1 caregivers	TBI	Multicomponent	3 month	Association staff	Education Communication	Education Communication	↑education and communication
Isaki *et al.*[61]	U.S.A	Exploratory	To investigated the use of therapeutic writing for counseling long term caregivers of spouses with brain injury and neurogenic communication disorders.	3 participants	BI	Single component	3 months to complete the therapeutic writing task.	Researcher	none	Diagnosis, anger, grief, and similarities in coping mechanisms	Therapeutic writing appears to be a promising technique for counseling caregivers.
Klonoff *et al.*[62]	U.S.A	Case study	To describe the FEM	none	BI	Single component.	none	none	none	none	How to introduce FEM as a therapeutic tool in multiple therapy settings in a holistic milieu.
Kreutzer *et al.*[37]	U.S.A	Descriptive	To describe caregivers' and patients' helpfulness and goal attainment ratings of the Brain Injury Family Intervention, and evaluate their perceptions of most important things learned.	76 caregivers and 76 patients	ABI	Multicomponent	over ten weeks during 5x 2h intervention sessions	Clinician	Session Report Learning Survey Family Support Program Satisfaction Survey	Session Report Learning Survey Family Support Program Satisfaction Survey	BIFI topics were relevant and consistent with program goals.
Lundberg[78]	Sweden	Case study	To understand how information and communication technology can provide support to elderly family caregivers.	10 family households equipped	Stroke	Multicomponent	Regular group meeting on 2 years couple with technology	Municipality team	none	General education	+ To be included in a group & recognized as caregivers ↑Education
Morris & Morris[79]	U.K.	Exploratory	To examine stroke patients', carers' and volunteer supporters' experiences of peer support groups during hospital rehabilitation	10 peer supporters	Stroke	Multicomponent	Bi-weekly	Staff members	none	Practical issues Staff presence Similarity-difference Value of peers	+ Helpful information, advice, making new connections ↑awareness about stroke

Author	Country	Design	Aim & Purpose	Pop. sample size	Type of ABI	Type of Intervention	Delivery mode & Duration	Providers	Types of outcomes		Significant findings
									Patient	Family member / Caregiver	
Norup *et al.*[39]	Denmark	Descriptive	The present study assessed the amount of neuropsychological support, potential association between relatives' outcomes and NP treatment.	26 dyads	TBI	Multicomponent	6 sessions with a neuropsychologist during hospitalization.	NP	Functional measure Injury severity	Anxiety / depression Quality of life Amount / number of sessions	Relatives' symptoms of anxiety at admission were associated with the number of sessions as well as the amount of support.
Östlund *et al.*[80]	Sweden	Descriptive	To describe the experiences family members how participated in a series of 3 nurse-led family conversations that were offered in each family's home.	12 adult family members	Stroke	Single component	Series of three 1-h every 2 weeks	RN	Acceptability Experiences	Acceptability Experiences	+ Unique experience, possibilities for relational sharing and meaningful conversations as well as changes in family functioning
Portillo *et al.*[81]	Spain	Action research	To determine the rationale, effectiveness and adequacy of a nurse-led social rehabilitation program implemented with neurological patients and their carers.	IG: 17 patients and 16 relatives CG: 19 relatives and 17 patients 37 nurses	Other	Single component	4 sessions	RN	Daily living activities Social life	Daily living activities Social life	↑ Realistic expectations, positive attitudes towards social life, and developed a wider variety of choices for social changes.
Simpson *et al.*[96]	Australia	Observational	To describe the social worker's intervention for TBI families	27 families	TBI	Single component	Meeting during hospitalization	2 graduate social workers.	Content Intensity	Content Intensity	The most frequent interventions were counseling, education, and case management.
Stone[63]	U.S.A	Descriptive	The aim of this project was to test the use of web-based resources to enhance the preparedness and satisfaction of such caregivers.	70 patients and 79 caregivers	BI	Multicomponent	website	RN	none	Preparedness Satisfaction	↑Preparedness
Straits-Troster *et al.*[64]	U.S.A	Descriptive	To evaluate the feasibility, acceptability, and helpfulness of implementation of multifamily group treatment for VA and their families or caregivers.	8 dyads	TBI	Single component	2-3 individual family meetings and 9 months of bimonthly group meetings.	Therapist	Problems experienced Helpful aspects of treatment Implementation	Problems experienced Helpful aspects of treatment Implementation	Highly acceptable
Wilkinson *et al.*[82]	U.K	Case study	This single-case intervention study aims to advance research into interaction-focused intervention for aphasia	1 couple	Other	Single component	8 interventions sessions at home once a week, lasting 1-2 hours	Therapist	Conversation characteristics, Impact of intervention on conversation	Conversation characteristics, Impact of intervention on conversation	Changes in the couple's conversational behaviors.

IG: Intervention Group
CG: Control Group

RN: Registered Nurse
PT: Physical Therapist

NP: Neuro Psychologist
OT: Occupational Therapist

Table 2 Core components of selected interventions

	Number of core component	Emotionnal Support	Education	Coping Skills	Information	Problem-Solving Skills	Coordination	Psychoeducation	Prevention	Health Managment	Communication Skills	Neurobehavioural	Cognitive Behavioural TTT	Relationship Support	Advocacy	Family Involvment	Relaxation	Physical Activities	Multifamily Group TTT	Instrumental Support	Psychosocial Support	Therapeutic writing	Family Health Conversation	Family Experiential Model	Social Work
Bakas *et al.*[31] **Bakas *et al.*[32]** **Bakas *et al.*[33]**	**7**	X	X	X	X	X	X													X					
Fortune *et al.*[73]	**6**	X		X					X	X	X						X								
Ostwald *et al.*[48]	**6**	X	X	X	X			X	X																
Damianakis *et al.*[95]	**5**	X		X	X	X				X															
Eames *et al.*[86]	**5**	X	X		X		X													X					
Backhaus *et al.*[43]	**5**	X		X		X		X					X												
Backhaus *et al.*[50]	**5**	X		X				X					X	X											
Egan *et al.*[89]	**4**	X	X				X								X										
Marsden *et al.*[92]	**4**		X						X	X								X							
Blom Johansson *et al.*[77]	**3**	X			X						X														
Hirsch *et al.*[66]	**3**	X	X		X																				
Franzen-Dahlin *et al.*[65]	**3**	X	X				X																		
Gerbe & Gargaro[98]	**3**	X	X																	X					
Godwin *et al.*[59]	**3**	X	X	X																					
Hanks *et al.*[45]	**3**	X	X			X																			
Inci & Temel[67]	**3**	X	X			X																			
King *et al.*[34] **King *et al.*[35]**	**3**			X		X											X								
Kreutzer *et al.*[36] **Kreutzer *et al.*[37]** **Kreutzer *et al.*[38]**	**3**	X	X	X																					
Mackenzie *et al.*[75]	**3**	X	X								X														
Moriarty *et al.*[47]	**3**	X		X																X					
Shyu *et al.*[41] **Shyu *et al.*[42]**	**3**		X				X			X															
Cameron *et al.*[101]	**2**	X			X																				
Lundberg[78]	**2**		X		X																				
Perrin *et al.*[55]	**2**				X			X																	
Chang *et al.*[88]	**2**									X						X									
Geurtsen *et al.*[74]	**2**	X	X																						
Hernandez *et al.*[60]	**2**		X				X																		
Kim *et al.*[90]	**2**		X																		X				

	Number of core component	Emotionnal Support	Education	Coping Skills	Information	Problem-Solving Skills	Coordination	Psychoeducation	Prevention	Health Managment	Communication Skills	Neurobehavioural	Cognitive Behavioural TTT	Relationship Support	Advocacy	Family Involvment	Relaxation	Physical Activities	Multifamily Group TTT	Instrumental Support	Psychosocial Support	Therapeutic writing	Family Health Conversation	Family Experiential Model	Social Work
Malini[91]	**2**	X	X																						
McLaughlin *et al.*[46]	**2**	X													X										
Mores *et al.*[8]	**2**	X	X																						
Morris & Morris[79]	**2**	X									X														
Norup *et al.*[39] **Norup *et al.*[40]**	**2**	X						X																	
Oupra *et al.*[93]	**2**	X	X																						
Pierce *et al.*[57]	**2**	X	X																						
Powell *et al.*[49]	**2**		X			X																			
Stone[63]	**2**						X			X															
Aguirrezabal *et al.*[69]	**1**		X																						
Bishop *et al.*[51]	**1**							X																	
Brown *et al.*[52]	**1**														X										
Charles *et al.*[97]	**1**																		X						
Elliott *et al.*[44]	**1**		X																						
Isaki *et al.*[61]	**1**																					X			
Klonoff *et al.*[62]	**1**																							X	
Knapp *et al.*[53]	**1**		X																						
Lutz *et al.*[54]	**1**						X																		
Östlund *et al.*[80]	**1**																						X		
Palmisano and Arco[99]	**1**			X																					
Perlick *et al.*[56]	**1**																		X						
Pfeiffer *et al.*[68]	**1**					X																			
Portillo *et al.*[81]	**1**		X																						
Rivera *et al.*[70]	**1**					X																			
Robinson-Smith *et al.*[58]	**1**											X													
Simpson *et al.*[96]	**1**																								X
Straits-Troster *et al.*[64]	**1**																		X						
Togher *et al.*[94]	**1**										X														
Wilkinson *et al.*[82]	**1**											X													
Wilz & Barskova[76]	**1**												X												

Table 3: Frequency, duration, delivery mode and moment of delivery for the interventions included

Frequency	N	*Duration*	N	*Delivery mode*	N	*Moment*	N
Weekly to bi-weekly	18	< 3 months	30	Meetings	33	Acute phase	5
Monthly to bi-monthly	13	3-6 months	12	Phones calls	3	Discharge period	12
Irregular	25	6 months - 1 year	11	Technology	6	Rehabilitation	9
1 Episode	3	> 1 year	6	Combined	17	Chronic phase	36
Others	5	No detail	5	Not applicable	5	Not applicable	2

Table 4: Characteristics of the secondary studies included

Author	Country	Design	Aims and Purpose	Pop. sample size	Type of ABI	Type of Intervention	Outcomes		Key findings
							Patient	Family/ caregiver	
Lee *et al.*[103]	U.S.A	Meta-analysis	To examine the effectiveness of interventions for improving mental health of caregivers of people with stroke	5 RCT	Stroke	Education & support Interventions	none	Mental health	Overall intervention improved mental health for caregivers
Aldehaim *et al.*[104]	U.S.A	Systematic. review	To evaluate the evidence for technology-based interventions addressing stroke caregivers needs.	4 RCT	Stroke	Technology-based intervention	none	Depression Problem-solving skills Burden Health status Social support Preparedness Healthcare utilization	• 2 studies reported significant decreases in caregivers' depression symptoms. • One study showed an improvement in caregivers' preparedness. • One study showed a decrease in healthcare utilization.
Bakas *et al.*[120]	U.S.A	Critical analysis	To criticize, analyse, and synthesize the evidence on the impact of family caregiver and dyad interventions on stroke survivor and caregiver outcomes.	32 studies	Stroke	No specific intervention	Not specified	Not specified	• Intervention for caregivers are more recommanded if caregivers'outcomes are desired (Level A) • Stroke dyad interventions are more recommanded when survivor outcomes are most desired (Level A) • Intervention combining skill building and psycho-education are more recommanded (Level A) • Tailored intervention are more recommanded (Level A) • Face to face and/or by phone are recommanded (Level A) • 5-9 sessions are recommanded (Level A)
Boschen *et al.*[24]	Canada	Critical appraisal	To criticize the quality of the evidence	31 studies	ABI and chronic conditions	Family Interventions	Not specified	Not specified	• Lack of methodological rigor • No strong evidence supporting any specific intervention for families with ABI

Author	Country	Design	Aims and Purpose	Pop. sample size	Type of ABI	Type of Intervention	Outcomes		Key findings
							Patient	Family/ caregiver	
Brereton *et al.*[106]	U.K.	Systematic review	To examine the effectiveness of interventions for adult family carers of people with stroke	8 RCT	Stroke	No specific intervention	Not specified	Not specified	• No conclusions on effectiveness • Some benefits are reported for all interventions • Generally low of quality
Cheng *et al.*[25]	China	Systematic review	To identify evidence related to the effectiveness of psychosocial interventions for family caregivers on the psychosocial and physical wellbeing.	18 studies	Stroke	Psychosocial interventions	Psychosocial and physical wellbeing	Psychosocial and physical wellbeing	• Based on two studies testing counselling interventions a significant improvement in family functioning immediately post-intervention was found. • Psychosocial intervention improved satisfaction for caregivers
Cheng *et al.*[107]	China	Meta-analysis	To evaluate the effectiveness of psychosocial interventions for family caregivers on their psychosocial and physical wellbeing, quality of life, and the use of healthcare resources by stroke survivors.	18 studies	Stroke	Psychoeducation and social support group	Use of healthcare resources	Psychosocial and physical wellbeing, Quality of life	Psychoeducation improved family functioning, caregivers' psychosocial wellbeing and decreased use of healthcare resources by stroke survivors
Corry *et al.*[119]	Ireland	Umbrella review	To evaluate the effectiveness of interventions to support caregivers of people with selected chronic conditions.	8 systematic review	Chronic conditions	Support intervention	none	Not specified	• Education and support program improved caregiver quality of life. • Information-giving interventions improved caregiver knowledge.
Eldred & Sykes[108]	U.K.	Systematic Review	To identify which psychosocial interventions have been tested for effectiveness in informal carers of survivors of stroke.	7 RCT	Stroke	Psychosocial intervention	none	Psychological health Physical health, Quality of life Burden	Education and counselling intervention showed more favourable outcomes on global family functionning.
Ireland *et al.*[109]	Canada	Review	To analyse if intervention that provide information improve outcomes for patients with stroke or their carers	17 trials	Stroke	Information interventions	Clinical outcomes	Subjective outcomes	Information intervention can reduced patient depression score but not carer stress.
Jones *et al.*[110]	Ireland	Retrospective case review	To present a case series detailing the psychosocial challenges and outcomes of three patients and their partners	3 dyads	Stroke	Interdisciplinary intervention	Psychosocial issues	Psychosocial issues	• Key intervention identified targeted communication between family members, facilitation of emotional expression and coordination • Interventions targeted at psychosocial issues resulted in a positive outcome.
Johansson & Wild[111]	Austria	Systematic Review	To review literature about tele rehabilitation in stroke care	9 studies	Stroke	Telerehabilitation interventions	none	Not specified	Most studies showed positive trends but due to the quality of the evidence i slow.
Legg[115]	U.K.	Systematic Review	To describe health effects of these interventions in a stroke context	8 RCT	Stroke	Support and information; and psycho-educational	none	Stress Strain Anxiety, Depression Health-related quality of life	A single-center study suggested that vocational training-type interventions may reduce stress and strain.
Loupis & Faux[112]	Australia	Literature Review	This review aimed to integrate and analyze current knowledge on family conferences in the inpatient stroke rehabilitation setting.	23 studies	Stroke	Family conferences	none	Not specified	Intervention may be enhanced by being more proactive rather than reactive.
Luaute *et al.*[118]	France	Systematic Review	To determine follow-up measures beyond the hospital stay that could reduce behavioral disorders, depression and constraints for closed ones.	6 studies	BI	No specific intervention	none	Behavioral disorders, depression and constraints	Most studies showed positive trends but due to the level of evidence, no conclusion could be drawn,
Rietdijk *et al.*[117]	Australia	Systematic Review	To describe the effectiveness of using telehealth programs to provide training or support to family members of people with traumatic brain injury.	7 RCT	TBI	Telehealth programs	none	Not specified	Telehealth programs are feasible, with positive outcomes reported.
Smith *et al.*[113]	U.K.	Systematic Review	To assess the effectiveness of information provision strategies in improving the outcome for stroke patients and/or their identified caregivers.	11 studies	Stroke	Information provision	Knowledge about stroke and impact on mood	Knowledge about stroke and impact on mood	• ↑ knowledge, patient depression, and satisfaction. • Active strategies had a greater effect on patient anxiety and depression.
Vloothuis *et al.*[114]	Netherland	Systematic Review	To determine if caregiver-mediated exercises improve functional ability and health-related quality of life in people with stroke, and to determine the effect on caregiver burden.	9 RCT	Stroke	Caregiver-mediated exercise	Functional ability Health-related quality of life	Functional ability Health-related quality of life Burden.	Most studies showed positive trends but due to the level of evidence, no conclusion could be drawn,
Fisher *et al.*[116]	Australia	Systematic Review	To examine family involvement in the management of behavioral problems following ABI in the community.	10 studies	ABI	Behaviour Management	none	Burden Stress Depression Family functioning, Knowledge, Satisfaction	• Low to moderate quality evidence • Five studies showed significant findings supporting family involvment if interventions combined education and individualized behabioural plans.

Appendix

Appendix 1: Full search strategies

EMBASE.com
2026 references from 2007 to April 5th 2017
('cerebrovascular accident'/exp OR 'head injury'/de OR 'brain injury'/de OR 'acquired brain injury'/de OR 'brain concussion'/de OR 'brain contusion'/de OR 'brain damage'/de OR 'traumatic brain injury'/de OR 'brain ischemia'/de OR 'brain hemorrhage'/exp OR 'brain infarction'/de OR (((cerebrovascular OR "cerebro vascular" OR brain OR cerebral OR craniocerebral) NEAR/3 (accident* OR trauma* OR injur*)) OR (Head NEXT/1 (injur* OR trauma*)) OR "acute cerebrovascular lesion" OR Stroke OR CVA OR CVAs):ab,ti) AND ('family centered care'/exp OR 'family nursing'/exp OR 'family counseling'/de OR (('family'/exp OR 'caregiver'/exp OR 'relative'/exp OR 'caregiver burden'/de OR (family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship):ti) AND ('nursing intervention'/de OR 'nursing process'/de OR 'counseling'/exp OR 'group therapy'/de OR 'support group'/de OR 'peer group'/de OR 'education program'/de OR 'health education'/de OR 'health program'/de OR 'workshop'/de)) OR ((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) NEAR/4 (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR "peer group" OR "peer groups" OR psychoeducation OR education OR oriented OR centered OR centred OR "discussion group" OR "discussion groups" OR "support group" OR "support groups" OR workshop*)):ab,ti OR ((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) AND (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR psychoeducation OR education* OR oriented OR centered OR centred OR group* OR workshop*)):ti) NOT (('juvenile'/exp OR 'childhood injury'/de OR 'child health care'/exp OR 'child care'/exp OR 'pediatrics'/exp) NOT 'adult'/exp)

Medline Ovid SP
Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present
922 references from 2007 to April 5th 2017
(exp Stroke/ OR Craniocerebral Trauma/ OR brain injuries/ OR exp brain hemorrhage, traumatic/ OR exp brain injuries, diffuse/ OR exp brain injuries, traumatic/ OR exp brain injury, chronic/ OR exp Brain Ischemia/ OR exp intracranial hemorrhage, traumatic/ OR (((cerebrovascular OR "cerebro vascular" OR brain OR cerebral OR craniocerebral) ADJ3 (accident* OR trauma* OR injur*)) OR (Head ADJ (injur* OR trauma*)) OR "acute cerebrovascular lesion" OR Stroke OR CVA OR CVAs).ab,ti.) AND (Family Nursing/ OR exp Caregivers/ed OR exp Family/ed OR ((exp Family/ OR exp Caregivers/ OR exp Family health/ OR (family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship).ti.) AND (Nursing process/ OR counseling/ OR exp Psychotherapy, Group/ OR Self-Help Groups/ OR Peer Group/ OR Health Education/)) OR ((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) ADJ4 (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR "peer group" OR "peer groups" OR psychoeducation OR education OR oriented OR centered OR centred OR "discussion group" OR "discussion groups" OR "support group" OR "support groups" OR workshop*)).ab,ti. OR ((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) AND (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR psychoeducation OR education* OR oriented OR centered OR centred OR group* OR workshop*)).ti.) NOT ((adolescent/ or exp child/ or exp infant/) NOT (adult children/ or exp adult/))

PubMed.gov
Strategy limited to references not indexed with MeSH terms
50 references from 2007 to April 5th 2017

(cerebrovascular accident*[tiab] OR cerebro vascular accident*[tiab] OR cerebrovascular trauma*[tiab] OR cerebro vascular trauma*[tiab] OR craniocerebral trauma*[tiab] OR brain trauma*[tiab] OR brain injur*[tiab] OR Head injur*[tiab] OR head trauma*[tiab] OR "acute cerebrovascular lesion"[tiab] OR Stroke[tiab] OR CVA[tiab] OR CVAs[tiab]) AND (family[ti] OR families[ti] OR caregiver*[ti] OR carer*[ti] OR careprovider*[ti] OR caretaker*[ti] OR relatives[ti] OR couple[ti] OR couples[ti] OR spous*[ti] OR kinship) AND (Intervention*[ti] OR program*[ti] OR "nurse led"[ti] OR support*[ti] OR training[ti] OR counsel*[ti] OR "skill-building"[ti] OR "peer group"[ti] OR "peer groups"[ti] OR psychoeducation[ti] OR education*[ti] OR oriented[ti] OR centered[ti] OR centred[ti] OR group[ti] OR groups[ti] OR workshop*[ti]) NOT "medline"[sb]

Cochrane Library Wiley
Cochrane Database of Systematic Reviews : Issue 4 of 12, April 2017
Database of Abstracts of Reviews of Effect : Issue 2 of 4, April 2015
Cochrane Central Register of Controlled Trials : Issue 3 of 12, March 2017
301 references from 2007 to April 5th 2017
(((cerebrovascular OR "cerebro vascular" OR brain OR cerebral OR craniocerebral) NEAR/3 (accident* OR trauma* OR injur*)) OR (Head NEXT/1 (injur* OR trauma*)) OR "acute cerebrovascular lesion" OR Stroke OR CVA OR CVAs):ab,ti AND (((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) NEAR/4 (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR "peer group" OR "peer groups" OR psychoeducation OR education OR oriented OR centered OR centred OR "discussion group" OR "discussion groups" OR "support group" OR "support groups" OR workshop*)):ab,ti OR ((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) AND (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR psychoeducation OR education* OR oriented OR centered OR centred OR group* OR workshop*)):ti)

PsycINFO Ovid SP
PsycINFO 1806 to March Week 4 2017
547 references from 2007 to April 5th 2017
(cerebrovascular accidents/ OR cerebral hemorrhage/ OR exp cerebral ischemia/ OR exp traumatic brain injury/ OR exp head injuries/ OR (((cerebrovascular OR "cerebro vascular" OR brain OR cerebral OR craniocerebral) ADJ3 (accident* OR trauma* OR injur*)) OR (Head ADJ (injur* OR trauma*)) OR "acute cerebrovascular lesion" OR Stroke OR CVA OR CVAs).ab,ti.) AND (family intervention/ OR ((family/ OR family members/ or parents/ or siblings/ or exp spouses/ or exp couples/ OR (family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship).ti.) AND (counseling/ OR group counseling/ OR peer counseling/ OR support groups/ OR intervention/ OR group intervention/ OR health education/)) OR ((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) ADJ4 (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR "peer group" OR "peer groups" OR psychoeducation OR education OR oriented OR centered OR centred OR "discussion group" OR "discussion groups" OR "support group" OR "support groups" OR workshop*)).ab,ti. OR ((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) AND (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR psychoeducation OR education* OR oriented OR centered OR centred OR group* OR workshop*)).ti.)
Limite: NOT (limit to (100 childhood <birth to age 12 yrs> or 200 adolescence <age 13 to 17 yrs>) NOT to "300 adulthood <age 18 yrs and older>")

CINAHL Full text -Ebsco
673 references from 2007 to April 5th 2017
((MH "Stroke+") OR (MH "Head Injuries") OR (MH "Brain Injuries+") OR (MH "Cerebral Ischemia") OR (MH "Intracranial Hemorrhage+") OR TI (((cerebrovascular OR "cerebro vascular" OR brain OR cerebral OR craniocerebral) N3 (accident* OR trauma* OR injur*)) OR (Head W1 (injur* OR trauma*)) OR "acute cerebrovascular lesion" OR Stroke OR CVA OR CVAs) OR AB (((cerebrovascular OR "cerebro vascular"

OR brain OR cerebral OR craniocerebral) N3 (accident* OR trauma* OR injur*)) OR (Head W1 (injur* OR trauma*)) OR "acute cerebrovascular lesion" OR Stroke OR CVA OR CVAs)) AND ((MH "Family Nursing") OR (MH "Family+/ED") OR (MH "Caregivers/ED") OR (((MH "Family+") OR (MH "Caregivers") OR (MH "Caregiver Burden") OR (MH "Caregiver Support") OR TI (family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship)) AND ((MH "Nursing Process+") OR (MH "Counseling+") OR (MH "Peer Group") OR (MH "Support Groups") OR (MH "Psychotherapy, Group+") OR (MH "Health Education"))) OR AB ((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) N4 (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR "peer group" OR "peer groups" OR psychoeducation OR education OR oriented OR centered OR centred OR "discussion group" OR "discussion groups" OR "support group" OR "support groups" OR workshop*)) OR TI ((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) AND (Intervention* OR program* OR "nurse led" OR support* OR training OR counsel* OR "skill-building" OR psychoeducation OR education* OR oriented OR centered OR centred OR group* OR workshop*))) NOT (((MH "Child+") OR (MH "Child Care+") OR (MH "Pediatrics+") OR (MH "Adolescence+")) NOT ((MH "Adult+") OR (MH "Adult Children")))

Joanna Briggs Institute EBP Database – Ovid SP:
4 references from 2007 to April 6th 2017
((cerebrovascular accident* or cerebro vascular accident* or cerebrovascular trauma* or cerebro vascular trauma* or craniocerebral trauma* or brain trauma* or brain injur* or Head injur* or head trauma* or "acute cerebrovascular lesion" or Stroke or CVA or CVAs) and (family or families or caregiver* or carer* or careprovider* or caretaker* or relatives or couple or couples or spous* or kinship) and (Intervention* or program* or "nurse led" or support* or training or counsel* or "skill-building" or "peer group" or "peer groups" or psychoeducation or education* or oriented or centered or centred or group or groups or workshop*)).ti,sh,hw

Web of Science Core collection*
407 references from 2007 to April 6th 2017
TS=((("cerebrovascular" OR "cerebro vascular" OR "brain" OR "cerebral" OR "craniocerebral") NEAR/3 ("accident" OR "accidents" OR "trauma" OR "injury" OR "injuries")) OR "Head injury" OR "Head injuries" OR "Head trauma" OR "acute cerebrovascular lesion" OR "Stroke" OR "CVA" OR "CVAs") AND TI=(("family" OR "families" OR "caregiver" OR "carer" OR "careprovider" OR "caretaker" OR "relatives" OR "couple" OR "couples" OR "spous" OR "kinship" OR "caregivers" OR "carers" OR "careproviders" OR "caretakers" OR "spouses" OR "spousal") AND ("Intervention" OR "program" OR "Interventions" OR "programs" OR "programme" OR "programmes" OR "nurse led" OR support* OR training OR "counselling" OR "skill-building" OR "psychoeducation" OR "education" OR "educational" OR "oriented" OR "centered" OR "centred" OR "group" OR "workshop" OR "groups" OR "workshops"))

* The Core Collection includes the following databases: Science Citation Index Expanded (1900-present), Social Sciences Citation Index (1900-present), Arts & Humanities Citation Index (1975-present), Conference Proceedings Citation Index- Science (1990-present), Conference Proceedings Citation Index- Social Science & Humanities (1990-present), Book Citation Index– Science (2005-present), Book Citation Index– Social Sciences & Humanities (2005-present), Emerging Sources Citation Index (2015-present), Current Chemical Reactions (1985-present), (Includes Institut National de la Propriete Industrielle structure data back to 1840), Index Chemicus (1993-present)

ProQuest dissertations and theses
192 references on Novembre 1st 2017 (no date restriction)
ALL(((cerebrovascular OR "cerebro vascular" OR brain OR cerebral) PRE/3 (accident* OR trauma* OR injur*)) OR "acute cerebrovascular lesion" OR Stroke OR (Head PRE/1 (injur* OR trauma*))) AND (ALL((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) NEAR/5 (Intervention* OR Program* OR "nurse led" OR Oriented OR

Centered OR Centred OR counsel* OR education OR "skill-building" OR "peer group" OR "peer groups" OR "discussion group" OR "discussion groups" OR "support group" OR "support groups" OR Workshop*)) OR TI((family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR couple OR couples OR spous* OR kinship) NEAR/5 (Intervention* OR Program* OR "nurse led" OR Oriented OR Centered OR Centred OR counsel* OR education OR "skill-building" OR "peer group" OR "peer groups" OR "discussion group" OR "discussion groups" OR "support group" OR "support groups" OR Workshop*)))

OpenGrey
http://www.opengrey.eu/
13 references on Novembre 1st 2017 (no date restriction)
("Cerebro vascular accident" OR "Cerebro vascular accidents" OR "Cerebro vascular trauma" OR "Cerebrovascular accident" OR "Cerebrovascular accidents" OR "Cerebrovascular trauma" OR "Cerebrovascular injury" OR "Cerebrovascular injuries" OR "craniocerebral trauma" OR "craniocerebral injury" OR "craniocerebral injuries" OR "brain trauma" OR "brain injury" OR "brain injuries" OR "Head injury" OR "Head injuries" OR "head trauma" OR "acute cerebrovascular lesion" OR Stroke OR CVA OR CVAs) AND (family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR spous*) AND (Intervention* OR "nurse led" OR "skill-building" OR "peer group" OR "peer groups" OR "discussion group" OR "discussion groups" OR "support group" OR "support groups" OR Workshop*)

DART-Europe
http://www.dart-europe.eu/
62 references on Novembre 1st 2017 (no date restriction)
("Cerebro vascular accident" OR "Cerebro vascular accidents" OR "Cerebro vascular trauma" OR "Cerebrovascular accident" OR "Cerebrovascular accidents" OR "Cerebrovascular trauma" OR "Cerebrovascular injury" OR "Cerebrovascular injuries" OR "craniocerebral trauma" OR "craniocerebral injury" OR "craniocerebral injuries" OR "brain trauma" OR "brain injury" OR "brain injuries" OR "Head injury" OR "Head injuries" OR "head trauma" OR "acute cerebrovascular lesion" OR Stroke OR CVA OR CVAs) AND (family OR families OR caregiver* OR carer* OR careprovider* OR caretaker* OR relatives OR spous*) AND (Intervention* OR "nurse led" OR "skill-building" OR Workshop*)

Bielefeld University Library
https://www.base-search.net
34 references on November 1st 2017 (Search in title and limited to text documents, no date restriction)
Keywords used:
Family(ies)/ caregiver(s)/carer(s)/relative(s) intervention(s)
AND
("Cerebro vascular accident" "Cerebro vascular accidents" "Cerebrovascular accident" "Cerebrovascular accidents" "craniocerebral trauma" "brain trauma" "brain injury" "brain injuries" "Head injury" "Head injuries" "head trauma" Stroke CVA CVAs)

Clinicaltrials.gov
https://clinicaltrials.gov/
67 studies on Novembre 1st 2017 (no date restriction)
Condition /Disease: ((cerebrovascular OR "cerebro vascular" OR brain OR cerebral OR craniocerebral OR head) AND (accident OR accidents OR trauma OR injury OR injuries)) OR Stroke OR CVA OR CVAs
Title: family OR families OR caregiver OR carer OR careprovider OR caretaker OR caregivers OR carers OR careproviders OR caretakers OR spouse OR spouses OR relatives
Applied Filters: Adult (18–65) /Senior (66+)

ICTRP: WHO International Clinical Trials Registry Platform
http://apps.who.int/trialsearch/
144 trials on November 1st 2017 (no date restriction)

Title: family OR families OR caregiver OR carer OR careprovider OR caretaker OR caregivers OR carers OR careproviders OR caretakers

Condition / **Disease**: Cerebrovascular accident OR Cerebrovascular accidents OR craniocerebral trauma OR brain trauma OR brain injury OR brain injuries OR Head injury OR Head injuries OR head trauma OR Stroke

Appendix 2: Full description of frequency, amount of sessions, duration, delivery mode and moment of delivery for the included interventions

Author	Frequency	Total amount of sessions	Duration	Delivery mode	Moment
Aguirrezabal *et al.*[69]	1 session	2 hours (1 x 2 hours)	< 3 months	Meetings	Acute phase
Backhaus *et al.*[43]	Weekly sessions	24 hours (12 x 2 hours)	3-6 months	Meetings	Rehabilitation phase
Backhaus *et al.*[50]	Irregular sessions	26 hours (13 x 2 hours)	3-6 months	Meetings	Chronic phase
Bakas *et al.*[33] **Bakas *et al.*[31]** **Bakas *et al.*[32]**	Weekly sessions	3 hours (9 x 20 minutes)	< 3 months	Phone calls	Early discharge period
Bishop *et al.*[51]	Irregular sessions	4.7 hours (13 x 15 minutes)	6 months - 1 year	Phone calls	Transition period after discharge
Blom Johansson *et al.*[77]	Weekly sessions	4.5 hours (6x 45 minutes)	< 3 months	Meetings	Rehabilitation
Brown *et al.*[52]	Monthly	24 hours (4 x 6 hours)	3-6 months	Meetings	Chronic phase
Cameron *et al.*[101]	Irregular session	3-12 session 75-285 minutes	3-6 months	Meeting & phone calls	From acute phase
Chang *et al.*[88]	Weekly	12 sessions	3-6 months	Meetings	Chronic phase
Charles *et al.*[97]	Bi monthly	24 hours (12 X 2 hours)	6 months - 1 year	Group Meeting	Chronic phase
Damianakis *et al.*[95]	Weekly	10 hours (10 x 1 hour)	< 3 months	Meeting on line	Chronic phase
Eames *et al.*[86]	Irregular sessions	6 sessions	< 3 months	Meeting + phone calls + helpline	Pre and post discharge
Egan *et al.*[89]	Monthly to bi-monthly	1-8 sessions	3-6 months	Phone calls + meetings	Chronic phase
Elliott *et al.*[44]	Irregular sessions	12 sessions	> 1 year	In-home meetings + phone calls	Chronic phase
Fortune *et al.*[73]	Irregular sessions	9 sessions	not specified	Meeting	Rehabilitation and chronic phases
Franzen-Dahlin *et al.*[65]	Monthly	7 sessions	> 1 year	Group Meetings	Stroke Unit
Gerber & Gargaro[98]	Bi-weekly	No details	> 1 year	Non detail	Chronic phase
Geurtsen *et al.*[74]	Irregular session	250 hours per person	6 months - 1 year	Meetings	Chronic phase
Godwin *et al.*[59]	None	None	None	none	none
Hanks *et al.*[45]	Irregular	29 sessions	> 1 year	Meeting + phone calls	Pre and post discharge
Hernandez *et al.*[60]	Not applicable	Not applicable	3-6 months	Clinical Video telehealth	Post discharge
Hirsch *et al.*[66]	Irregular	Unlimited	< 3 months	Meeting	Rehabilitation phase
Inci & Temel[67]	Weekly	15 hours (10x 90 minutes)	< 3 months	Group Meetings	Chronic phase
Isaki *et al.*[61]	Irregular	3 months	3-6 months	Non	Chronic phase
Ivey-Williams *et al.*[84]	Weekly	8 hours	< 3 months	Meetings	Chronic phase
Kim *et al.*[90]	Irregular	15 sessions	3-6 months	Meeting + phone calls	Pre and post discharge
King *et al.*[34] **King *et al.*[35]**	Irregular	10 sessions	< 3 months	Meetings + phone calls	Pre and post discharge
Klonoff *et al.*[62]	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
Knapp *et al.*[53]	1 session	1 session	< 3 months	Virtual dialogue	Rehabilitation phase
Kreutzer *et al.*[36] **Kreutzer *et al.*[37]** **Kreutzer, *et al.*[38]**	Bi-monthly	10 hours	< 3 months	Meetings	Chronic phase
Lloyd[71]	Weekly to bi-weekly	6 hours	< 3 months	Meetings	Chronic phase
Lundberg[78]	Monthly to bimonthly	>24 sessions + use of Internet program	> 1 year	Group meetings + technology	Chronic phase
Lutz *et al.*[54]	Irregular	14 days	< 3 months	Home messaging device	Chronic phase
Mackenzie *et al.*[75]	Weekly	16 hours	< 3 months	Meeting	Chronic phase
Malini[91]	Bi monthly	6 sessions	3 -6 months	Meeting	Chronic phase
Marsden *et al.*[92]	Weekly	7 hours	< 3 months	Meetings	Chronic phase
McLaughlin *et al.*[46]	Irregular	Multimedia	< 3 months	Multimedia	Chronic phase
McMakin [83]	Weekly	10 hours	< 3 months	Group meetings	Chronic phase
Mores *et al.*[8]	Weekly	8 hours (4 x 2 hours)	< 3 months	Group meetings	Chronic phase

Moriarty *et al.*[47]	Bi-monthly	8 sessions	3-6 months	Home visits + phone calls	Chronic phase
Morris & Morris[79]	Bi-weekly	13 sessions (20 hours)	< 3 months	Group meeting	Rehabilitation phase
Norup *et al.*[39]	Irregular	6 sessions	< 3 months	Meeting	Acute to rehabilitation phase
Norup *et al.*[40]	1 session	1-1.5 hours	< 3 months	Meetings	Acute phase
Östlund *et al.*[80]	Bi-monthly	6 hours (6 x 1 hour)	< 3 months	In-home meeting	Chronic phase
Ostwald *et al.*[48]	Irregular	6 sessions and mails	6 months - 1 year	Meetings + mails + other material	Chronic phase
Oupra *et al.*[93]	Monthly	3 sessions	3 - 6 months	Meetings + phone calls	Pre and post discharge
Palmisano & Arko[99]	Weekly	1-hour home visits or telephone calls	< 3 months	Meetings + phone calls	Chronic phase
Perlick *et al.*[56]	Bimonthly	18 sessions	6 months - 1 year	Individual + Group meetings	Chronic phase
Perrin[85]	Not specified	Not specified	Not specified	Not specified	Pre and post discharge
Perrin *et al.*[55]	Irregular	5 sessions	< 3 months	Meeting + videophone calls	Pre and post discharge
Pfeiffer *et al.*[68]	Irregular	20 sessions	> 1 year	In-home meetings	Chronic phase
Pierce *et al.*[57]	Irregular	Not specified	6 months - 1 year	Web-based and email	Chronic phase
Portillo *et al.*[81]	Not specified	4 sessions	6 months - 1 year	Meetings	Rehabilitation
Powell *et al.*[49]	Bi-monthyl	10 calls maximum	6 months - 1 year	Phone calls	Chronic phase
Rivera *et al.*[70]	Irregular	12 session	6 months - 1 year	In-home sessions and phone calls	Chronic phase
Robinson-Smith *et al.*[58]	Irregular	6 sessions	< 3 months	In-home sessions	Chronic phase
Shyu *et al.*[41] **Shyu *et al.*[42]**	Irregular sessions	5-6 sessions	< 3 months	Meetings + phone calls	Pre and post discharge
Simpson *et al.*[96]	Irregular sessions	24 hours of services (mean)	< 3 months	Meetings	Rehabilitation phase
Stamatakis *et al.*[72]	Weekly	10 hours (5 x 2 hours)	< 3 months	Meetings	Chronic phase
Stone *et al.*[63]	Irregular	Use of website	not specified	Website	Post discharge
Straits-Troster *et al.*[64]	Irregular	12 sessions	6 months - 1 year	Meetings	Chronic phase
Togher *et al.*[94]	Weekly	25 hours (10 x 2.5 hours)	< 3 months	Meetings	Chronic phase
Wilkinson *et al.*[82]	Weekly	16 hours (8 x 2 hours)	< 3 months	In-home meetings	Chronic phase
Wilz & Barskova[76]	Bi-monthly	30 hours (15 x 2 hours)	6 months - 1 year	Meetings	Rehabilitation phase