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

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Review question: The aim of this scoping review is to examine the range and nature of family-oriented interventions that have been developed and/or tested for people with acquired brain injuries (ABI) and their families in all settings. Specifically the review questions are:

- What are the aims and characteristics (type, delivery mode and duration, provider) of 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?

Keywords: Brain injury; caregiver; family; family oriented-intervention; scoping review

Introduction

Acquired brain injuries (ABI) are one of the leading causes of disability in adults worldwide. The main forms of traumatic brain injuries (TBI) are haematoma, concussion and cerebral concussion: the severity of injury ranges from altered mental status to total loss of consciousness. Traumatic injuries are often due to road accidents, falls, gunshot-related wounds or sport accidents. Non-traumatic injuries, such as stroke, tumors and aneurysms, are mainly due to vascular malformations, brain infections or anoxia.

The effects of ABI, whether they are trauma-related or not, on motor and cognitive functions can be significant and may result in major changes in life for the patients and their families. Depending on the severity of the injury and the spread of the lesion, ABI can temporarily impact on physical health (i.e. quadriplegia, paraplegia or hemi-syndrome), cognitive functions (i.e. attention deficit disorder, memory loss or concentration troubles), behavior (i.e. managing emotion, stress or problem-solving disabilities), and personality. In the acute phase, care provided by multidisciplinary teams mainly aim to maintain neurological and homeostatic stability, and to preserve vital functions. Some institutions offer opportunities for ABI patients 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.

Cognitive impairments can be more difficult to diagnose, compared to physical injuries, and they often have devastating consequences. In the chronic phase, many patients present difficulties for finding work, mainly due to communication impairments, the inability to use everyday life technology (i.e. answering the phone or turning on a computer) and carry out ADL. The inability of these patients to work impacts negatively on the economic situation of their family as well as their social standing.

Due to the sudden and unpredictability of ABI, patients and their families find themselves in situations that they are unable to handle. The consequences of ABI on family members may affect their dynamics and functioning, resulting in the need for role and responsibility readjustments.
review including 22 original articles reported the impact of support for patients with TBI and their families. The results showed that nurses’ interventions should include three dimensions of support: the informational, the emotional and the practical, 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 promoting 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 caregiver satisfaction. In the chronic phase of the injury, relatives of people with ABI report some dissatisfaction with their life as a whole and a high level of burden. Burden is characterized by the persons’ individuals feelings of being overwhelmed, being forced to change their life plans or be confined. Burden is multidimensional and can be exacerbated by remote access to care, limited patients’ 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. Family members of patients with ABI often report poor family functioning, which does not improve with time.

Supporting families of patients with ABI may include various interventions modalities, such as support groups for family members of patients requiring intensive care, communication interventions, and/or flexible visiting hours. To date, a few studies have explored interventions targeted at the patient and their family for this population. A review of the literature published in 2007 included 31 experimental and quasi-experimental studies with family interventions targeted at carers of patients with brain injury (four studies) and other chronic conditions (27 studies). 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 rigor of the selected studies, and, importantly, 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. However, to the best of our knowledge, no study determining the effect of interventions for families of patients with ABI in general (and not specific to a particular condition, such as stroke or TBI) has been reported. Given the nature, extent and heterogeneity of the current literature, it would thus be relevant to map out the different types of family-orientated interventions designed for all types of ABI patients and their families. This step is essential prior to implementing any support intervention during the course of injury and recovery. Therefore, a scoping review will assist in clarifying the core components of family interventions tested in the ABI population at the different stages of care, from the acute to the chronic phase of injury. It will also inform on the relevant outcome measures used in the studies. Ultimately, the results of this scoping review will contribute to the evaluation of the necessity for performing a systematic review of effect.

A preliminary search of the literature in the JBI Database of Systematic Reviews and Implementation Reports, Cochrane Database of Systematic Reviews, Centre for Reviews and Dissemination (CRD) Database, PROSPERO, PubMed and CINAHL showed no reviews on this topic (published or in process).

**Inclusion criteria**

**Participants**
The review will consider studies that include participants who are:

a) Adult patients with acquired brain injury (TBI, stroke, anoxia, tumor), from any gender, culture and ethnicity admitted to a healthcare facility.

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

b) Family members: All members of the family of patients with acquired brain injury including spouse, partner, children, parents, siblings who are caregivers or non-caregivers, as defined by a group of people linked by a deep emotional attachment and a sense of belonging.
**Concept**

The concept of this scoping review is all types of interventions or activities designed for families of patients with ABI. This definition may include but is not limited to: any type of intervention or activity designed to improve outcomes for the patient and their family members. The nature of intervention/action could be education, emotional or information, focusing on either family/caregivers only, or family/caregivers and patient. Whether the intervention is built with a systemic or a family-centered care framework will be documented. Interventions focusing on patients only will be excluded.

**Context**

This scoping review will consider studies conducted in all care settings (e.g. intensive care, acute care, inpatient, inpatient rehabilitation, outpatient rehabilitation, chronic care, homecare, community setting) in any country.

**Types of studies**

This review will consider 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 studies and mixed methods studies.

This review will also consider descriptive observational study designs, including case series, individual case reports and descriptive cross-sectional studies, meta-analysis and gray literature. Published study protocols, text, opinion and policy documents will be excluded.

**Methods**

**Search strategy**

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be conducted.

The first step is an initial limited search of MEDLINE and CINAHL. It will be followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. The second step is a second search using all identified keywords and index terms across all included databases. The third step will be to search for additional studies amongst all identified reports’ and articles’ reference lists. Studies published in English and in French will be included. The period from January 2007 to the present will be considered; the rapid evolution of technology for intervention (i.e.: electronic devices, web-based intervention) and reanimation process (i.e. medical progress, rehabilitation access) justifies this timeframe.

**Information sources**

Sources to be search will include:

- MEDLINE
- PubMed (search will be limited to references not indexed in MEDLINE)
- CINAHL
- Cochrane
- Joanna Briggs Institute EBP Database Ovid SP
- Embase
- PsycINFO
- Web of Science Core Collection

The search for unpublished studies will include OpenGrey, ProQuest Dissertations and Theses, DART Europe E-theses Portal, WHO International Clinical Trials Registry Platform, ClinicalTrials.gov, BASE (Bielefeld Academic Search Engine).

Initials keywords are: brain injuries, stroke, cranio-cerebral trauma, cerebrovascular accident, CVA, head injury, family, caregivers, professional-family relations, parent, family nursing, family intervention, adult. See Appendix I for the initial search strategy for PubMed.

Authors of primary studies will be contacted for further information if it is deemed relevant by the reviewers.

**Study selection**

Following the search, all identified citations will be collated and uploaded into a citation management system (Endnote X7 [Clarivate Analytics, PA, USA]), and duplicates removed. Titles and abstracts will then be screened by two independent reviewers (VdG and LR) for assessment against the inclusion and exclusion criteria for the review using the web-based citation management system Rayyan (Qatar Computing Research Institute, Doha, Qatar). Disagreements between the two reviewers will be resolved with a third independent reviewer (ASR). A similar process will be used for full-text inclusion in the review. Details of included studies in the review will be imported into Joanna Briggs Institute System for the Unified Management, Assessment
and Review of Information (JBI SUMARI). Reasons for exclusion will be documented in an appendix in the final systematic review report. The results of the search will be reported in details in the final report and presented in the recommended JBI adapted flow diagram for scoping review.28

**Data extraction**

A charting table will be developed as recommended by the JBI methodology for scoping reviews to record the key information of the selected studies, including:28

- **Author(s)**
- **Year of publication**
- **Origin/country of origin (where the study was published or 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 that relate to the scoping review question**

**Data synthesis**

As recommended in the JBI scoping review guidelines, the results will be presented in a tabular form with a narrative summary relating the key findings.28

The results will be presented following the PCC concept and the main conceptual categories obtaining during the extraction of the data (i.e. population, type of intervention, aim, methodology, setting, key findings and gaps in the research). These categories will be related to the questions of this scoping review.

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**References**


Appendix I: Initial and limited search strategy for PubMed


#1 OR #2 AND adult[MeSH]
Appendix II: Data extraction tool

<table>
<thead>
<tr>
<th>Title/author /year of publication /country</th>
<th>Aims/purpose</th>
<th>Design</th>
<th>Population Sample size</th>
<th>Type of intervention</th>
<th>Duration of intervention</th>
<th>Provider</th>
<th>Types of outcomes</th>
<th>Key findings</th>
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SYSTEMATIC REVIEW PROTOCOL

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