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Manuscript title:

***Behaviour management following Acquired Brain Injury (ABI)
in Community Settings: A Family Perspective
Systematic Review***

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Keywords: behaviour, family, community, acquired brain injury, systematic review

Abstract

Objectives: To examine family involvement in the management of behavioural problems following ABI in the community.

Research Design: Systematic literature review.

Methods: Six electronic databases relevant to the field of brain injury were searched between 1980-2013. Citation indexes were used, and references from articles hand searched for further literature. Studies that met the broad inclusion criteria were screened for relevance, and articles selected for full-text review independently considered by two reviewers. Those found to be relevant were analysed using PEDro and McMasters critical appraisal tools.

Results: Three hundred and three studies were identified after duplicates were removed and 56 were assessed for relevance, yielding 10 studies for review. Although the majority of studies were weak in design, 5 revealed significant findings supportive of family involvement in the management of behavioural problems following ABI, especially where interventions consisted of both educational components and individualised behavioural plans. Findings revealed no significant changes in family burden following behavioural interventions.

Conclusions: There is limited research and lack of high evidence studies evaluating family involvement in behaviour management following ABI; therefore no conclusions can be drawn regarding its efficacy. More research is needed, with larger sample sizes and more rigorous design, including proper comparison groups.

Keywords: behaviour, family, community, acquired brain injury, systematic review

Introduction

Individuals often experience significant physical, cognitive and behavioural sequelae following brain injury¹⁻³. Depending on the nature and location of the brain injury, the extent of damage and long-term implications will vary for each individual^{1,4}. Behavioural issues are considered one of the leading causes of frustration in the care of individuals with acquired brain injury (ABI) in rehabilitative settings⁵ and also the most detrimental in the long-term as the individual attempts to reintegrate back into the community⁶. Families experience significant burden in coming to terms with the brain injury, and are then faced with the challenges associated with caring for and managing the person's behaviours within their homes and communities⁷.

Behaviour problems following ABI can manifest in a variety of ways. Although physical and verbal aggression are the most commonly investigated⁸⁻¹⁴, there are other serious behavioural outcomes following ABI. These include sexually inappropriate behaviours¹⁵⁻¹⁷, socially inappropriate behaviours^{2,6}, absconding¹⁸, apathy^{19,20}, lack of initiation⁶, reduced social skills²¹, disinhibition²², irritability^{19,23}, and mood disorders^{24,25}. Whether behavioural problems consist of violent displays of aggression, acts of public sexuality or lack of initiation, these behaviours present unique difficulties for individuals and their family within the community. As a specific definition of behavioural issues remains elusive, the term 'behavioural problems' will be adopted throughout this paper in attempt to encapsulate this broad range of behaviours often resulting from brain injury.

Many individuals with brain injury, whether mild, moderate or severe, receive little or no formal rehabilitation, being discharged home with limited follow-up²⁶. Families often then take on the primary role of caregiver^{26,27}; may be left to grapple with cognitive and behavioural changes, and required to reorganise their everyday life to adjust to their new role²⁷⁻²⁹. Considering the extent of responsibility families have in caring for their loved one following brain injury²⁶, one might presume that families would be well informed regarding the brain injury and potential behavioural changes. However, the literature suggests this is

not the case, with families reporting unmet information needs^{28,30-33}. In studies conducted by Murray et al.³², instruction on how to manage the individual when they are 'upset' or acting 'strange' was the highest rated unmet need for families. This suggests that families should have access to education materials regarding behaviour management and instruction specifically related to their family member with an ABI³² and to environmental contexts in which behaviours occur.

Individuals with ABI living in community settings spend most of their time in their home environment (e.g. home, parent's home, supported accommodation, rental or public housing) and social environment (e.g. supermarkets, shopping centres and sporting facilities). Traditionally, controlled environments emphasising structure and consistency have been constructed within institutional settings (e.g. in-patient rehabilitation facilities). However, these settings are not a long-term option and are in very short supply, restricted only to individuals who exhibit severe behavioural problems³⁴. The challenge, then, is for brain injury services to develop ways of supporting the person with ABI and managing their behaviours in the community, in less intensive and less restrictive settings^{34,35}, taking into account family support needs.

Whilst there is a considerable amount of literature reporting the effectiveness of behavioural interventions following ABI³⁶⁻³⁸, there is very little information available regarding brain injury service solutions for community-based behaviour management interventions³⁴. There has also been an emphasis on paid staff in community management following brain injury^{15,39}. This paper therefore offers a unique and novel perspective, focusing on family members who do not choose this caregiving role, but rather may find themselves in this position^{26,27} without the skills and support needed to effectively manage behavioural problems³². The question is then; how can family members be supported effectively in order to manage these behaviours in the community? This review presents the first step in addressing this question, by examining the evidence underpinning family involvement in the management of behavioural problems following ABI in the community.

This review is inclusive of studies involving active family participation in the management of behavioural problems; whether exclusively, or in collaboration with paid workers, as opposed to interventions carried out by paid workers only. This review has also included studies broadly concerning individuals with ABI, as interventions are being examined at the behavioural level. As stated by Carnevale et al.⁴⁰, individuals with both TBI and other forms of ABI exhibit behaviour problems, and effective interventions need to be developed for both.

Methods

A systematic review was conducted in accordance with the PRISMA guidelines⁴¹. A search of the literature from 1980 to 2013 was conducted using the following electronic databases: CINAHL (Cumulative Index to Nursing & Allied Health Literature), Informit, OvidSP (ovid Medline and PsycINFO), Cochrane and PEDro. Subject headings and keyword searches were developed under the following three main themes: behavioural problems/intervention (e.g. Behavioural Disturbances, Behaviour Therapy and Disruptive Behaviour), family involvement (e.g. Family-Centred Care, Home Nursing, and Family Therapy) and brain injury (combined using the Boolean operator 'AND'). The associated medical sub-headings (MeSH) were used preferentially; these were expanded upon and further clarified through articles identified through preliminary searches of each database, using mapped subheadings relating to brain injuries, behaviour change and behaviour therapy.

The preliminary searches of each database consisted of the following subject headings: CINAHL; 'Disruptive Behavior', 'Social Behaviour' and 'Behavioural changes', combined using the Boolean operator 'OR', combined with 'Brain Injury' using the Boolean operator 'AND'; Medline; 'Social Behavior Disorders' and 'Behavior Therapy' united by 'OR' and combined with 'Brain Injury' using 'AND': PsycINFO; 'Behaviour Disorders' and 'Behaviour Therapy' united using 'OR', combined with 'Brain Damage' ('OR') 'Head Injuries' using 'AND'. The subject headings used to classify relevant articles identified through this

search were then used to further refine the search strategy for this review (see Appendix A for details). MeSH terms varied across the selected databases, which resulted in database being searched separately.

The search strategy for Informit, PEDro and Cochrane consisted of key words, as mapped subject headings were not provided. Keyword searches were developed under the same themes: Behavioural problems/intervention (e.g. 'Behavioural modification', 'Challenging Behaviour', 'Harmful Behaviour', 'Aggression', and 'Psychiatric'), Family involvement (e.g. 'Home', 'In-home', 'Community', 'Caregiver' and 'Spouse') and Brain Injury (e.g. 'Head Injured', 'ABI' and 'TBI'), using alternative spellings.

To ensure saturation of relevant literature, further strategies were also utilised. Additional papers were identified using the citation indexes 'Scopus' and 'Web of Knowledge', and by conducting hand searches of the reference list of relevant articles.

Study selection

The initial inclusion criteria were kept broad during the electronic and manual searches, to prevent the exclusion of potentially relevant articles. Inclusion limits were also not placed on study design, as it was anticipated that the available literature regarding behavioural interventions involving family would use a variety of study designs.

This review only included studies that were published in English, with a primary population of individuals with ABI who were 16 years or older and sustained an ABI at 15 years or above. The reason for implementing this inclusion criterion was to target families that had a sense of the person before the injury, with their experience of knowing and living with the person then changed dramatically; whereas for ABI in younger relatives or from birth, the accommodation to the change would likely take a different path.

The studies were also required to directly concern the involvement of 'family members' (including spouses, friends, and unpaid caregivers [but inclusive of those receiving government allowances]) in behaviour management within home and community settings.

Studies were excluded if they explored the experience of paid support workers exclusively. Studies were also excluded if they did not include the families' involvement in the management of behaviours.

The primary researcher screened titles/abstracts for full-text review. If there was uncertainty regarding the inclusion of articles, a second reviewer was consulted. Articles selected for full-text review were then independently considered by two reviewers. Through consensus, both reviewers then agreed on the final articles to be rated and analysed.

Assessment of methodological quality

Articles that met inclusion criteria were then assessed by both reviewers, with consensus reached for items scored using the following critical appraisal tools: McMasters (for quantitative and qualitative studies)^{42,43}; and PEDro (for RCTs)⁴⁴. These tools are divided into sections corresponding to various aspects of study validity. The McMasters critical review tool for quantitative studies consists of sections regarding study design, sample selection, reliability and validity of outcome measures, data collection, withdrawals and dropouts, the avoidance of contamination (if participants in the control group inadvertently receive treatment) and cointervention (if participants receive another form of treatment at the same time as the study intervention), the appropriateness of analysis method/s and conclusions made. For each section of the instrument, a rating of 'yes', 'no', 'not addressed', or 'not applicable' was assigned to the study. The PEDro was originally designed for the assessment of RCTs for physical therapy, but has since been used to assess psychological interventions⁴⁵. The PEDro scale consists of 11 items regarding the random allocation of participants, concealed allocation and blinding of participants and assessors, and the reporting of statistical comparisons and measures of variability. Each item was evaluated and totaled to give a total score out of 10 (scoring items two to 11 according to the PEDro guidelines⁴⁴). The studies were also rated according to their level of evidence as recommended by the Australian National Health and Medical Research Council (NHMRC)⁴⁶.

The NHMRC is the peak funding body for medical research in Australia and was established to develop and maintain health standards⁴⁷. The NHMRC provides a medical research grading system used to assess the reliability of medical publications⁴⁶.

Data extraction and synthesis

Study details were collected from each article, including study design, participant characteristics, inclusion/exclusion criteria, study design, outcomes and main findings. A qualitative narrative synthesis of the findings was then performed using this information, describing both consistencies and discrepancies between the studies. A meta-analysis was not possible given that studies differed significantly with respect to design and outcomes.

Results

A total of 303 studies were identified after duplicate removal and screening. An additional 41 studies were identified through the use of citation indexes and hand searching reference lists. Studies were reviewed for inclusion relevant to the content of their title and abstract, resulting in the exclusion of 271 studies. Fifty-six full-text studies were evaluated for inclusion (refer to Figure 1). Forty-six studies were excluded for the following reasons: 21 studies did not specifically concern the family members' experience of managing behaviours; nine studies explored the implications of ABI on family members and/or importance of family intervention, but were not specific to behaviour management; eight studies consisted of participants who were not primarily diagnosed with ABI or were not specific to behaviour management; four studies concerned participants who did not fit age criteria (≥ 16 yrs) for this review; and the remaining four studies explored implications of ABI or available support for families, but were also not specific to behaviour management. Nine articles were independently selected by the two reviewers, with consensus achieved regarding the inclusion of a 10th paper.

Insert Figure 1.

Study Characteristics

There were a total of 112 participants included across the 10 studies, including 77 males and 35 females (mean age 31.7yrs), with mild to severe ABI. Sample sizes in the studies were consistently low, ranging from 1-37 participants. The demographics and injury characteristics of participants in each study are presented in Table 1.

Three studies specifically concerned participants with traumatic brain injury (TBI)⁴⁸⁻⁵⁰, and the remaining studies consisted more broadly of participants with ABI. The cause of brain injury varied significantly, with TBI resulting from motor vehicle accidents^{40,51,52}, falls, construction-related accidents and assaults^{40,51}, and ABIs resulting from meningitis⁵³, anoxia, stroke, arteriovenous malformations, encephalopathy, electrocution^{40,51}, aneurysm⁴⁰, and brain tumors^{52,54}. Five articles did not specify the cause of brain injury^{48-50,55,56}.

Insert Table 1.

The presence of a behavioural impairment related to brain injury was required for participant inclusion in three studies; however, no detail was given regarding the definition of 'behavioural impairment'^{40,51,55}. Participant inclusion in the study conducted by Arco and Bishop⁵³ required that parents rated at least 15/20 in the Head Injury Behaviour Scale (HIBS) and behaviour caused moderate or severe distress for one or both parents, or one or both parents reported a high level of burden on the Care Burden Scale (CBS). The remaining six studies did not specify inclusion requirements relating to the presence of behavioural problems. Five of the studies also excluded participants with a history of psychiatric disorders, developmental disability, or substance abuse^{40,51,52,55,56}.

The target behaviours varied significantly across the studies, including; aggressive/inappropriate behaviour (damaging property and verbal aggression), elopement,

disinhibited and potentially dangerous behaviour while driving⁴⁰, routine behaviours such as maintaining cleanliness of bathroom, independently collecting belongings required for day's activity and putting them away on return, communication with spouse regarding payment of bills and telephone messages⁵², independence carrying out morning routine (including preparing breakfast, sitting at dining table, and eating breakfast)⁵³, and 'temper outbursts'⁵⁶. Six studies did not provide details regarding problem behaviours exhibited by participants^{48-51,54,55}.

Family members involved in studies predominately included parents^{48-50,53,55} and spouses^{48,52,54}, and were also identified as 'relatives'⁵⁶, adult children⁵⁴ and 'other'⁴⁸. The remaining two studies did not specify the relationship of the caregiver to the individual with ABI^{40,51} (see Table 1). However, as 'family members' were involved within the baseline phase, it was inferred that they were included in the 'caregiver system'. Although this was not explicitly stated, the families' involvement was also not ruled out. For this reason these studies were included within this review. However, the inclusion of these studies should be viewed with caution.

These studies included a range of international perspectives: six studies were conducted in the USA; including New Jersey^{40,51,55}, West Texas⁴⁸ and Ohio^{49,50}. Three studies were conducted in Australia: Perth^{52,53} and Sydney⁵⁴, and one was conducted in the UK (city unspecified)⁵⁶.

Methodological assessment results

Overall, the studies included in this review were of poor quality. The highest quality studies consisted of two level II evidence⁴⁶ randomised controlled studies, with a mean score of 7/10 according the PEDro rating scale (see Table 2). All remaining studies consisted of level III-3 evidence studies⁴⁶, with a mean score of 7/12 according to the McMasters critical appraisal tool (with a maximum of 11 recorded for one study⁵²) (See Table 3). These studies

consisted of six single case designs^{48,49,52,53,55,56}, one single case design with a concurrent control group⁵⁰, and one pre-post test mixed-method study⁵⁴.

Insert Table 2.

Insert Table 3.

Interventions

An overview of studies included is presented in Table 4. The two highest evidence studies reviewed^{40,51}, evaluated a Natural Setting Behaviour Management (NSBM) program. A NSBM group (including education and an individualised behaviour program) was compared with an education only group, versus a control group. Although the sample sizes were limited (n=<40), and there was an overlap of an undisclosed number between samples⁴⁰, these studies make significant contributions to literature regarding behaviour management in non-specialised community settings.

The Natural Setting Behaviour Management (NSBM) program provides structured education and intervention to individuals with ABI in community settings, including home, work or school environments. The NSBM team in both of these studies consisted of doctoral-level psychologists and behaviour technicians working in collaboration with participants and caregivers^{40,51}. The first phase of the NSBM was consistent across these two studies, consisting of a three-week education phase. Participants and their caregivers in the NSBM (education and intervention) group and education-only group received education regarding common neurobehavioral sequelae of brain injury, with a gradual emphasis on the neurological factors underlying the particular target behaviours and practical behavior management techniques. The second phase consisted of an individualised NSBM behaviour plan, which was developed in collaboration with participants and caregivers focusing specifically on targeted behaviours. Caregivers were responsible for implementing

interventions, with interactive sessions held with staff throughout this process to elicit problem-solving regarding modification of behaviours.

The effectiveness of web-based interventions was evaluated in three studies⁴⁸⁻⁵⁰. Two of these studies evaluated the outcome of a Teen Online Problem Solving intervention (TOPS) using the same sample group^{49,50}. The TOPS program consisted of 16 sessions, including 10 core sessions providing problem-solving, communication, and social skills training to family members. The remaining six sessions addressed content relating to the stressors and burdens of individual families. After completion of these self-directed exercises, the families met with a therapist via video-conference to review exercises and implement a 'problem-solving process'⁵⁰. The first study examined outcomes for participants with ABI and their parents relating to depression and parent-adolescent conflict⁵⁰, and the second study⁴⁹ evaluated the delivery of the TOPS program. The third web-based intervention⁴⁸ consisted of six videoconference sessions providing education and interactive problem solving for family members, evaluating their levels of perceived burden and satisfaction ratings.

Six studies involved community-based interventions, where family members were supported by professionals to develop individualised treatment plans in managing behavioural problems in their relatives with ABI^{40,51-53,55,56}. The remaining study evaluated the outcome of a half-day training workshop for family members of individuals with Primary Brain Tumour (PBT)⁵⁴. This session was delivered in a group format, consisting of five sections involving education and group discussions relating to behavioural and cognitive change following PBT, and management strategies⁵⁴.

Interventions were delivered by a range of health professionals, including neuropsychologists, clinical psychologists, behaviour technicians, counsellors, a Radiation Oncologist and a Neurosurgical Clinical Nurse Consultant. Three studies did not identify the profession/experience of the researchers facilitating interventions^{52,53,56}.

Insert Table 4.

Outcomes

Outcomes measured included: observed change in targeted behaviours; levels of burden; stress and depression experienced by family members; levels of family functioning; improved knowledge regarding ABI and compensatory strategies to manage behavioural/cognitive change following ABI; and, satisfaction with interventions among family members/caregivers. The outcome measures varied between studies (see Table 1), with those most utilised including: observation of target behaviours using structure checklists^{40,52,53,55,56}; subscales of the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS)^{40,51,52,57}; an adapted version of the Maslach Burnout Inventory (MBI)^{40,51,58}; attitudinal and satisfaction surveys^{48,49,55}; purpose-designed questionnaires^{52,54}; and interviews^{48,55}.

Of the five studies that recorded behaviour change following intervention^{40,52,53,55,56}, three reported significant improvement in target behaviours^{40,52,55}. However, only one of these studies consisted of an evidence class II RCT design⁴⁰ using reliable outcome measures. In this study a significant reduction in frequency of target behaviours was reported ($P < .002$) in the Natural Behaviour Setting Management (NSBM) group (education plus intervention) at three months post-intervention. Research conducted by Carnevale⁵⁵, which also evaluated the NSBM program, revealed 82% improvement of target behaviours among participants by the phaseout stage, with the greatest change occurring during the education phase (51%). Palisano and Arco⁵² reported improvement in independent behaviours in all three cases presented, with behaviours improving from a mean of 61% to 92% of task completion at one month follow-up. However, the reliability of these results is limited due to weak study design and data collection methods.

The two studies measuring caregiver burden^{51,52}, interestingly revealed no significant changes following behavioural interventions, even though improvements in target behaviours were reported.

Family members who participated in the Teen Online Problem Solving intervention (TOPS) reported significantly fewer internalising symptoms, lower levels of depression, and a reduction in conflict and problem issues with their relative with ABI⁵⁰ (see Table 4). Across the four studies that evaluated the caregivers' satisfaction with the intervention^{48,49,54,55}, results suggested families were satisfied with content, felt information presented was practical, and reported an increase in knowledge.

Methodological limitations

There were a number of methodological limitations consistently noted. Only 112 participants were included across the ten studies, significantly impacting the generalisability of results. Furthermore, only two studies consisted of RCT design^{40,51}, with the absence of comparison groups limiting outcome reliability of the remaining studies.

Further clarification was also needed with regard to participant inclusion criteria and family involvement in managing behaviours. The presence of behavioural impairment was required for participant inclusion in three studies^{40,51,55}; however, a definition of behavioural impairment was not given, and six studies did not provide details regarding the behaviour problems exhibited by participants^{48-51,54,55}.

The relationship of the caregiver to the individual with ABI was not specified in two studies^{40,51}, and in one study no detail was provided regarding the involvement of paid versus unpaid caregivers in the intervention⁵⁵. In an additional four studies, the extent of family involvement in managing behavioural problems was not clearly outlined^{49,50,52,56}.

There was also a lack of rigorous follow-up data specific to the improvement of target behaviours. The most reliable follow-up data was recorded following the RCT conducted by Carnevale et al.⁴⁰ at 30 weeks post-baseline. Carnevale⁵⁵ also collected follow-up data at 12

months post-baseline, however the validity of these results are limited due to weak study design and data collection methods. Of the remaining four studies that collected follow-up data^{48,49,51,52}, only one study reported on the frequency of target behaviours⁵², with data collected at one month post-intervention.

Discussion

This systematic review examined the evidence base for the efficacy of family involvement in behaviour management following ABI in community settings. While none of the studies provide sufficient evidence for how the involvement of family could be included in practice guidelines, they do indicate possible benefits of family involvement in behaviour management, and intervention techniques meriting further validation.

Methodological Assessment

Among the 10 articles meeting criteria for inclusion in this review, there were no evidence class I studies, and only two evidence class II studies consisting of RCT designs^{40,51}. This lack of high class research reflects the difficulty faced in selecting rigorous and appropriate research design to evaluate rehabilitation programs for individuals with ABI and their families⁵⁹. As individuals with ABI are typically heterogeneous, due to the diversity of brain injury¹, it can be difficult to describe a sample due to a lack of (adequate) records⁶⁰. This is evident from this review. In general, the studies have not provided adequate information on the population sample characteristics, definition of problem behaviours and methodology to allow for replication.

Furthermore, no studies provided information on the likelihood of the use of co-interventions. As stated by Comper et al.⁶¹, brain injury often results in a number of complaints, making it possible that individuals were receiving treatment for various symptoms while also taking part in the behavioural interventions. This is an important consideration, as behavioural problems may be present as a result of underlying factors,

including memory difficulties, and additional cognitive and physical impairments for which the individual may be receiving support.

The major limitation of the two evidence class II studies^{40,51} are the small, and overlapping, samples (n=37, n=27). This limits generalisability of results. Given the heterogeneity of this population⁴, larger samples are necessary if outcomes are to have sufficient statistical significance in detecting clinically meaningful changes⁶⁰. Furthermore, the involvement of family members was not clearly defined in either of these studies, limiting the reliability of results. However, findings do warrant further investigation of the efficacy of the NSBM program, with consideration of these methodological limitations.

There was also a lack of information provided across the studies relating to intervention techniques, participant demographics and family involvement. Wade and colleagues⁵⁰ did not provide detail regarding the individual 'problem-solving' process, and the extent to which the family was involved. Two studies^{49,50} did not provide specific age of participants (mean age = 15.03; range 11 -18yrs), so inclusion of these studies within this review should be viewed with caution. The separate roles of family and paid caregivers were also not defined within the intervention conducted by Carnevale⁵⁵. The people involved in the 'caregiver system' were identified for all participants, which included paid caregivers, such as a part-time attendant, private-duty nurses, school personnel, personal care attendants and supported employment personnel, as well as relatives of the participants with ABI. Throughout this article both 'caregivers' and 'family' appear to be referred to separately; however, it was not explicitly stated as to whether the 'caregiver' or 'family' member completed the caregiver attitude survey. Although the family member was included within the 'caregiver system', to what degree they were involved in the intervention is unknown. This limits the reliability of this study according to the inclusion requirements. Furthermore, results were reported in a purely descriptive manner, utilising case studies, and there was no mention of the use of standardised outcome measures, or whether decreases in behavioural problems reached statistical significance.

Arco and Bishop⁵³ presented three single case designs, with only one fitting the inclusion criteria for this study. The parents were trained to prompt their adult-child with ABI to independently carryout morning routine (preparing and eating breakfast). However, limited detail was provided regarding the training given to parents, prompts used and at what rate they were withdrawn. These methodological limitations, as well as the mixed and inconclusive findings of this study, also limit the applicability of results.

Five of the studies excluded participants with a history of psychiatric disorders, developmental disability, or substance abuse^{40,51,52,55,56}. While this ensures that behavioural problems relate specifically to the brain injury, it could also be argued that excluding these behaviours may result in a non-representative sample; preexisting behavioural/psychiatric disorders and substance abuse are reported risk factors for TBI^{62,63}, and can add to the complexity of management and coping for all concerned.

Interventions

All studies included in this review involved either an educational phase or family training relating to the use of checklists and management strategies. Education included information on common neurobehavioural sequelae of brain injury^{40,48-51,54,55}, including discussion relating to possible factors that contributed to the behaviour problem identified by each family^{40,51,55}. General principles of behaviour management were also provided, including antecedent and consequence analysis^{40,51,55}, identifying triggers and handling 'stressful situations'⁵⁶, and strategies to reinforce appropriate behaviours and the use of external cueing⁴⁹, problem-solving^{48,50}, and strategies for managing behavioural and cognitive changes after PBT⁵⁴. Families were trained in how to use observation checklists^{40,51,52,55}, and to prompt an individual with ABI in self-recording behaviours⁵³. Education delivered to families through the web-based interventions also included sessions more broadly relating to ABI, including topics relating to reduced memory and attention,

changes in language and social communication, reduced initiation and organisation⁴⁹, and social skills training⁵⁰.

The educational components included in these studies were not outlined in enough detail to replicate the content. However, the broad categories relating to common neurobehavioural sequelae and general principles of behaviour management were included across a majority of these studies^{40,48-51,54,55}. Carnevale and colleagues⁴⁰ delivered education using a standard protocol, and stated the NSBM training manual could be obtained for further detail. However, the author has been unsuccessful in making contact with the authors for this information.

There was great disparity in the behaviour problems identified by family members across the studies, including socially inappropriate behaviours (e.g. damaging property and verbal aggression) and apathy (limited independence in routine behaviours and organisation relating to daily activities), which is reflective of the wide range of behavioural problems reported following ABI within community settings^{6,19}. The broad scope *and* cause of behaviour problems adds to the complexity of conducting research in this field, and further highlights the importance of developing management approaches that are equally varied and individualised to target specific behaviour problems⁶⁴.

According to Prigatano⁶⁵, behavioural problems are not necessarily related to neurological impairment, but may constitute a reactionary behavioural disturbance. This assertion is based on research conducted by Hinkeldey and Corrigan²³ that indicates irritability following ABI correlates significantly with forgetfulness, symptoms of fatigue when other people are around, and experiencing difficulty following conversations. Anger and irritability can also arise from high levels of noise, specific activities, or the demands of therapy⁴. It is therefore important that families understand the basis of the behavioural changes, and are provided with strategies to identify triggers and antecedents. This is necessary in developing a complete picture of behavioural problems. Families should also be encouraged to focus on the individuals' strengths within a meaningful environment,

realising the individuals potential to replace problem behaviours with more adaptive ones^{4,66}.

The challenge then is to develop interventions that are specific to individual needs but also are methodologically sound, increasing reliability and allowing for replication. Although this was not achieved adequately by any of the studies reviewed, the RCT designs conducted by Carnevale et al.⁴⁰ and Carnevale et al.⁵¹ consist of research designs showing most potential towards this goal.

Outcomes

Significant findings were reported in 5 out of 10 studies^{40,50,52,54,55}, with results revealing significant improvement in target behaviours, caregiver satisfaction and improved knowledge relating to neurobehavioural sequelae following ABI and management strategies.

Findings suggest that education alone may not be sufficient in addressing long-term behavioural problems. Results reveal significant change in behaviour following intervention consisting of both an educational component and the development of individualised behaviour plans⁴⁰. The importance of providing education to family members has also been highlighted by Sander et al.⁴⁸, with participants reporting education sessions relating to the management of emotional and behavioural problems to be the most beneficial. This has also been emphasised in previous research³², in which families reported information on how to manage behavioural changes as the highest unmet need.

The study conducted by Carnevale et al.⁵¹ evaluated the effects of NSBM in reducing caregiver burden, revealing no significant changes following the intervention in any of the groups. As stated by Carnevale et al.⁵¹, these results suggest that initial levels of caregivers' burden and distress are highly predictive of these ratings at outcome, regardless of participation in behaviour intervention. These findings are also in consensus with studies conducted by Palmisano and Arco⁵², where there was no correlation between improvement of functional behavior and reported caregiver burden. It was suggested that possibly a more

general approach to behaviour management (not one that targets specific behaviours) might have a more positive impact on family burden⁵².

The studies included in this review support the importance of measuring levels of caregiver burden in conjunction with behaviour improvement following intervention. This will impact the future development of community-based behavioural support most beneficial to overall wellbeing and improved family functioning. These studies also support the need for further research identifying the relationship between behavioural disturbances and caregiver burden, which appears to be a complex and multilayered phenomenon⁶⁷. As reported by Marsh, Kersel, Havill and Sleigh⁶⁸, emotional difficulties, particularly anger and apathy, cause significant distress for caregivers. However, with regard to the impact that caregiving has on their own lives, caregivers are most distressed by the loss of personal free time⁶⁸. This suggests that even with the reduction of behavioural problems, levels of burden will remain high where individuals with ABI are dependent on their caregivers for assistance in daily routine tasks.

The web-based interventions were also supportive of family involvement in behaviour management, reporting positive outcomes relating to functioning and problem-solving skills⁵⁰, increased knowledge and satisfaction with intervention delivery^{48,49}. The study conducted by Wade et al.⁴⁹ also raised an important issue, with the inclusion of measures relating to families' perceptions of the ease of use and helpfulness of the videoconferences. The importance of the quality of this therapeutic relationship was not measured in any of the other studies reviewed. As stated by Cattelani et al.⁶⁹, if participants do not trust or respect the therapist they will be unlikely to cooperate and will therefore not benefit from the intervention as much as those with a positive attitude towards the working relationship. This issue should be addressed when evaluating the effectiveness of interventions tailored for individuals with behavioural problems following ABI⁶⁹.

Overall, there was a lack of adequate follow-up data recorded across all 10 studies relating to the impact the intervention had on target behaviours and burden experienced by

the family caregiver specific to behavioural problems. This was particularly evident following web-based interventions, where participants reported increased knowledge following intervention^{48,49}, but there was no follow-up examining the application of knowledge acquired by family members in managing behavioural problems.

Similarly, results of the study conducted by Whiting et al.⁵⁴ are limited as no follow-up data was collected to examine if new knowledge gained during the half-day workshop was applicable to the caregivers' daily experiences within community settings. The purpose-designed outcome measure used (SUM) in this study has also not been validated, limiting reliability of results.

Limitations

Although this systematic review uses valid methodologies in identifying articles, there are some limitations that should be recognised. Limitations to the search strategy may mean the review is not completely representative of the relevant literature. Specific conditions resulting in ABI, such as dementia, Parkinson's, and stroke, were not included as keyword searches. Specific cognitive and behavioural outcomes following ABI that present challenges, such as apathy and absconding were also not included as search terms. Furthermore, studies were only considered if they were published in English, and published in peer-reviewed journals or books. Therefore, studies were not considered if they were published in government documents and conference proceedings.

The author was also unsuccessful in making contact with researchers to acquire missing information and clarify study methodology; it is therefore possible that studies that did not sufficiently report on aspects of their methods received a low quality score, despite being well-conducted studies.

The critical appraisal tools used to evaluate the overall quality of the studies may have also limited conclusions made, as each section was weighted equally. For example, criteria

such as 'validity of outcome measure' and 'justification of sample size' contributed equally to the overall quality rating.

Implications for Practice and Research

The evidence supporting the involvement of family members in behavioural interventions carried out in community settings is promising, with improvements seen in target behaviours and high levels of satisfaction reported by family members. Results were supportive of multi-phase interventions, consisting of education components followed by the development of individualised treatment plans specific to the individuals' behavioural problems. However, due to the paucity of high evidence studies, no conclusions can be drawn regarding their efficacy. There were only two RCT studies included in this review, and these studies had a limited sample size ($n < 40$), and overlap in their sample group. The relationship between caregivers and participants with ABI were also not defined, limiting the reliability of conclusions drawn from this review regarding the involvement of family members in managing behavioural problems following ABI. More research is required, with larger sample sizes and more rigorous design including proper comparison groups, with RCTs being most desirable, and well designed $n=1$ trials. Studies should include more explicit detail regarding the relationship of the caregiver, the role of the caregiver within the behavioural intervention, and the specific target behaviours displayed by individuals with ABI. Studies should also examine the impact of family-led behavioural interventions on target behaviours and levels of family burden. It will only be when this is achieved that we can determine the efficacy of family involvement in managing behavioural problems.

Declarations of Interest

The authors report no declarations of interest. The authors alone are responsible for this work, and received no funding by any corporation or external party directly interested in the results.

References

1. Gelber DA, Callahan, C.D. Neurologic Examination of the Patient with Traumatic Brain Injury. In: Ashley MJ, editor. *Traumatic Brain Injury: Rehabilitation, Treatment, and Case Management*. 3rd ed. Broca Raton, FL: CRC Press; 2010. p 3-27.
2. Sabaz M, Simpson, G.K., Walker, A.J., Roger, J.M., Gillis, I., Strettles, B. Prevalence, comorbidities, and correlates of challenging behavior among community-dwelling adults with severe traumatic brain injury: A multicenter study. *Journal of Head Trauma Rehabilitation* 2014;29(2):E19-E30.
3. Ponsford JL, Downing, M.G., Olver, J., Ponsford, M., Acher, R., Carty, M., Spitz, G. . Longitudinal follow-up of patients with traumatic brain injury: Outcome at two, five, and ten years post-injury. *Journal of Neurotrauma* 2014;31(1):64-77.
4. Ponsford J, Sloan, S., & Snow, P. , editor. *Traumatic Brain Injury: Rehabilitation for everyday adaptive living*. 2nd ed. Hove, East Sussex: Psychology Press; 2013.
5. Lombard LA, Zafonte, R.D. Agitation After Traumatic Brain Injury: Considerations and Treatment Options. *American Journal of Physical Medicine & Rehabilitation* 2005.
6. Kelly G, Brown, S., Todd, J., Kremer, P. . Challenging behaviour profiles of people with acquired brain injury living in community settings. *brain injury* 2008;22(6):457–470.
7. Turner B, Fleming, J., Cornwell, P., Worrall, L. Ownsworth, T., Haines, T., Kendall, M., Chenoweth, L. A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers. *brain injury* 2007;21(11):1119–1130.
8. Alderman N. Contemporary approaches to the management of irritability and aggression following traumatic brain injury. *NEUROPSYCHOLOGICAL REHABILITATION* 2003;13(1/2):211–240.
9. Dyer KW, Bell, R., McCann, J., Rauch, R. . Aggression after traumatic brain injury: Analysing socially desirable responses and the nature of aggressive traits. *brain injury* 2006;20(11):1163–1173.
10. Giles GM, Scott, K., Manchester, D. Staff-reported antecedents to aggression in a post-acute brain injury treatment programme: What are they and what implications do they have for treatment? *Neuropsychological Rehabilitation* 2013.
11. Medd J, Tate, R.L. Evaluation of an Anger Management Therapy Programme Following Acquired Brain Injury: A Preliminary Study. *NEUROPSYCHOLOGICAL REHABILITATION* 2000;10(2):185–201.
12. Tateno A, Jorge, R.E., Robinson, R. G. Clinical correlates of aggressive behavior after traumatic brain injury. *The Journal of Neuropsychiatry and Clinical Neurosciences* 2003;15(2).
13. Willis TJ, LaVigna, G.W. The Safe Management of Physical Aggression Using Multi-Element Positive Practices in Community Settings. *J Head Trauma Rehabil* 2003;18(1):75-87.
14. Alderman N, Knight, C., Brooks, J. Rehabilitation Approaches to the Management of Aggressive Behaviour Disorders after Acquired Brain Injury. *Brain Impairment* 2013;14 (1):5-20.
15. Feeney TJ, Ylvisaker, M., Rosen, B.H., Greene, P. Community Supports for Individuals with Challenging Behavior after Brain Injury: An Analysis of the New York State Behavioral Resource Project. *J Head Trauma Rehabil* 2001;16(1):61–75.
16. Simpson G, Blaszczyński, A., Hodgkinson, A. . Sex Offending as a Psychosocial Sequela of Traumatic Brain Injury. *J Head Trauma Rehabil* 1999;14(6):567-580.

17. Simpson GK, Sabaz, M., Daher, M. Prevalence, clinical features, and correlates of inappropriate sexual behavior after traumatic brain injury: A multicenter study. *Journal of Head Trauma Rehabilitation* 2013;28(3):202-210.
18. Manchester D, Hodgkinson, A., Pfaff, A., & Nguyen, G. A non-aversive approach to reducing hospital absconding in a head-injured adolescent boy. *Brain Injury* 1997;11(4):271-277.
19. Johnson R, Balleny, H. Behaviour problems after brain injury: incidence and need for treatment. *Clin Rehabil* 1996;10:173-181.
20. Kant R, Duffy, J.D., Pivovarnik, A. Prevalence of apathy following head injury. *Brain Injury* 1998;12(1):87-92.
21. Kersel DA, Marsh, N.V., Havill, J.H. and Sleigh, J. W. Psychosocial functioning during the year following severe traumatic brain injury. *Brain Injury* 2001;15(8):683-696.
22. Starkstein S, & Robinson, R. Mechanism of Disinhibition After Brain Lesions. *The Journal of Nervous & Mental Disease* 1997;185(2):108-114.
23. Hinkeldey NS, Corrigan, J.D. The structure of head-injured patients' neurobehavioural complaints: a preliminary study. *Brain Injury* 1990;4(2):115-133.
24. Mathias JL, Coats, J.L. Emotional and Cognitive Sequelae to Mild Traumatic Brain Injury. *Journal of Clinical and Experimental Neuropsychology* 1999;21(2):200-215.
25. Gould KR, Ponsford, J.L., Spitz, G. Association between cognitive impairments and anxiety disorders following traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology* 2014;36(1):1-14.
26. Oddy M, and Herbert, C. Intervention with families following brain injury: Evidence-based practice. *NEUROPSYCHOLOGICAL REHABILITATION* 2003;13(1/2):259-273.
27. Nalder E, Fleming, J., Cornwell, P., Foster, M. Linked Lives: The Experiences of Family Caregivers During the Transition from Hospital to Home Following Traumatic Brain Injury. *Brain Impairment* 2012;13(1):108-122.
28. Turner B, Fleming, J., Ownsworth, T., Cornwell, P. Perceived service and support needs during transition from hospital to home following acquired brain injury. *Disability and Rehabilitation* 2011;33(10):818-829.
29. Jones L, Morris, R. Experiences of adult stroke survivors and their parent carers: a qualitative study. *Clinical Rehabilitation* 2013;27(3):272-280.
30. Hawley CA, Ward, A.B., Magnay, A.R., and Long, J. . Parental stress and burden following traumatic brain injury amongst children and adolescents. *Brain Injury* 2003;17(1):1-23.
31. Jumisko E, Lexell, J., Soederberg, S. Living With Moderate or Severe Traumatic Brain Injury: The Meaning of Family Members' Experiences. *Journal of Family Nursing* 2007;13(3):353-369.
32. Murray HM, Maslany, G.W., Jeffery, B. . Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Injury* 2006;20(6).
33. Watanabe Y, Shiel, A., McLellan, D.L., Kurihara, M., Hayashi, K. . The impact of traumatic brain injury on family members living with patients: a preliminary study in Japan and the UK. *Disability and Rehabilitation* 2001;23(9):370-378.
34. Kelly G, Parry, A. Managing Challenging Behaviour of People With Acquired Brain Injury in Community Settings: The First 7 Years of a Specialist Clinical Service. *Brain Impairment* 2008;9(3):293-304.
35. Kelly G, Todd, J., Simpson, G., Kremer, P., Martin, C. . The overt behaviour scale (OBS): A tool for measuring challenging behaviours following ABI in community settings. *Brain Injury* 2006;20(3):307-319.
36. Rothwell NA, LaVigna, G.W., Willis, T.J. A non-aversive rehabilitation approach for people with severe behavioural problems resulting from brain injury. *brain injury* 1999;13(7):521- 533.

37. Feeney T, Ylvisaker, M. Choice and routine: Antecedent behavioural interventions for adolescents with severe traumatic brain injury. *J Head Trauma Rehabil* 1995;10(3):71-86
38. Pace GM, Dunn, E.K., Luiselli, J.K., Cochran, C.R., & Skowron, J. Antecedent interventions in the management of maladaptive behaviours in a child with brain injury. *brain injury* 2005;19(5):365–369.
39. Alderman N, Wood, R.L. Neurobehavioural approaches to the rehabilitation of challenging behaviour. *NeuroRehabilitation* 2013;32(4):761-770.
40. Carnevale GJ, Anselmi, V., Johnston, M.V., Busichio, K., Walsh, V. A Natural Setting Behavior Management Program for Persons With Acquired Brain Injury: A Randomized Controlled Trial. *Arch Phys Med Rehabil* 2006;87:1289 – 1297.
41. Moher D, Liberati, A., Tetzlaff, J., Altman, D.G., The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Journal of Clinical Epidemiology* 2009;62:1006-1012.
42. Law M, Stewart, D., Pollock, N., Letts, L., Bosch, J., & Westmorland, M. 1998 29/01/2014. Critical Review Form: Quantitative Studies. http://www.srsmcmaster.ca/Portals/20/pdf/ebp/qualreview_version2.0.pdf. Accessed 2014 29/01/2014.
43. Letts L, Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M. 2007 29/01/2014. Critical Review Form: Qualitative Studies. http://www.srsmcmaster.ca/Portals/20/pdf/ebp/qualreview_version2.0.pdf%3E. Accessed 2014 29/01/2014.
44. Maher CG, Sherrington, C., Herbert, T.D., Moseley, A.M., Elkins, M. Reliability of the PEDro scale for rating quality of randomised controlled trials. *Physical Therapy* 2003;83(8):713-21.
45. Tate RL, Perdices, M., McDonald, S., Togher, L., Moseley, A., Winders, K., Kangas, M., Schultz, R., Smith, K. . Development of a database of rehabilitation therapies for the psychological consequences of acquired brain impairment. *Neuropsychological Rehabilitation* 2004;14(5):517-34.
46. NHMRC. 2009 15/02/2014. National Health and Medical Research Council. *Levels of evidence and grades for recommendations for guideline developers*. Canberra: National Health and Medical Research Council https://http://www.nhmrc.gov.au/ files_nhmrc/file/guidelines/developers/nhmrc_levels_grades_evidence_120423.pdf. Accessed 2014 15/02/2014.
47. NHMRC. 2014 24/10/14. NHMRC research funding datasets 1990-2013. <http://www.nhmrc.gov.au/grants/research-funding-statistics-and-data/nhmrc-research-funding-datasets-1990-2013%3E>. 24/10/14.
48. Sander M, Clark, A. N., Atchison, T. B., & Rueda, M. A Web-Based Videoconferencing Approach to Training Caregivers in Rural Areas to Compensate for Problems Related to Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation* 2009;24(4):248-261.
49. Wade SL, Walz, N. C., Carey, J. C., & Williams, K. M. . Brief Report: Description of Feasibility and Satisfaction Findings from an Innovative Online Family Problem-solving Intervention for Adolescents following Traumatic Brain Injury. *Journal of Pediatric Psychology* 2009;34(5):517-522.
50. Wade S.L. WNC, Carey J.C., Williams K.M. Preliminary Efficacy of a Web-Based Family Problem-Solving Treatment Program for Adolescents With Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation* 2008;23(6):370-378.
51. Carnevale GJ, Anselmi, V., Busichio, K., Millis, S.R. . Changes in Ratings of Caregiver Burden Following a Community-Based Behavior Management Program for Persons with Traumatic Brain Injury. *J Head Trauma Rehabil* 2002;17(2).

52. Palmisano B, & Arco, L. Changes in Functional Behaviour of Adults With Brain Injury and Spouse-Caregiver Burden With In-Home Neurobehavioural Intervention. *Behaviour Change* 2007;24(1):36-49.
53. Arco L, Bishop, J. Single Participant Studies in Positive Behaviour Support for Parents of Individuals With Brain Injuries. *BRAIN IMPAIRMENT* 2009;10(3):307-319.
54. Whiting DL, Simpson, G.K., Koh, E.-S., Wright, K.M., Simpson, T., & Firth, R. . A multi-tiered intervention to address behavioural and cognitive changes after diagnosis of primary brain tumour: A feasibility study. *Brain Injury* 2012;26(7-8):950-961.
55. Carnevale GJ. Natural-setting behavior management for individuals with traumatic brain injury: Results of a three-year caregiver training program. *J Head Trauma Rehabil* 1996;11(1).
56. McKinlay WW, Hickox, A. How can families help in the rehabilitation of the head injured? *J Head Trauma Rehabil* 1988;3(4):64-72.
57. Holroyd J. *Manual for the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members*. Brandon, VT: Clinical Psychology; 1987.
58. Maslach C, Jackson, S., & Leiter, M. , editor. *Maslach Burnout Inventory manual* 3rd ed. Palo Alto: Consulting Psychologists; 1996.
59. Baddeley A, Meade, T., Newcombe, F. . Design problems in research on rehabilitation after brain damage. *Int Rehab Med* 1980;2(3):138-142.
60. Smith LM, Godfrey, H. P. D. *Family Support Programs and Rehabilitation: A Cognitive-Behavioral Approach to Traumatic Brain Injury* New York: Plenum Press; 1995.
61. Comper P, Bisschop, S.M., Carnide, N., Tricco, A. . A systematic review of treatments for mild traumatic brain injury. *Brain Injury* 2005;19(11):863–880.
62. Drubach DA, Kelly, M.P., Winslow, M.M., Flynn, J.P. Substance abuse as a factor in the causality, severity, and recurrence rate of traumatic brain injury. *Maryland medical journal* 1993;42(10):989-993.
63. Rutter M. Psychological Sequelae of Brain Damage in Children. *The American Journal of Psychiatry* 1981;138(12):1533-1981.
64. Yody BB, Schaub, C., Conway, J., Peters, S., Strauss, D., Helsing, S. *Applied Behavior Management and Acquired Brain Injury: Approaches and Assessment*. *J Head Trauma Rehabil* 2000;15(4):1041–1060.
65. Prigatano GP. Personality disturbances associated with traumatic brain injury. *Journal of Consulting and Clinical Psychology* 1992;60(3):360-368.
66. Ylvisaker M, Turkstra, L.S., and Coelho, C. . Behavioral and Social Interventions for Individuals with Traumatic Brain Injury: A Summary of the Research with Clinical Implications. *BEHAVIORAL AND SOCIAL INTERVENTION* 2005;26(4):256-267.
67. Wells R, Dywan, J., and Dumas, J. Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury. *Brain Injury* 2005;19(13):1105-1115.
68. Marsh NV, Kersel, D.A., Havill, J.H., & Sleigh, J.W. . Caregiver burden at 1 year following severe traumatic brain injury. *Brain Injury* 1998;12(12):1045-1059.
69. Cattalani R, Zettin, M., and Zoccolotti, P. Rehabilitation Treatments for Adults with Behavioral and Psychosocial Disorders Following Acquired Brain Injury: A Systematic Review. *Neuropsychol Rev* 2010;20:52-85.

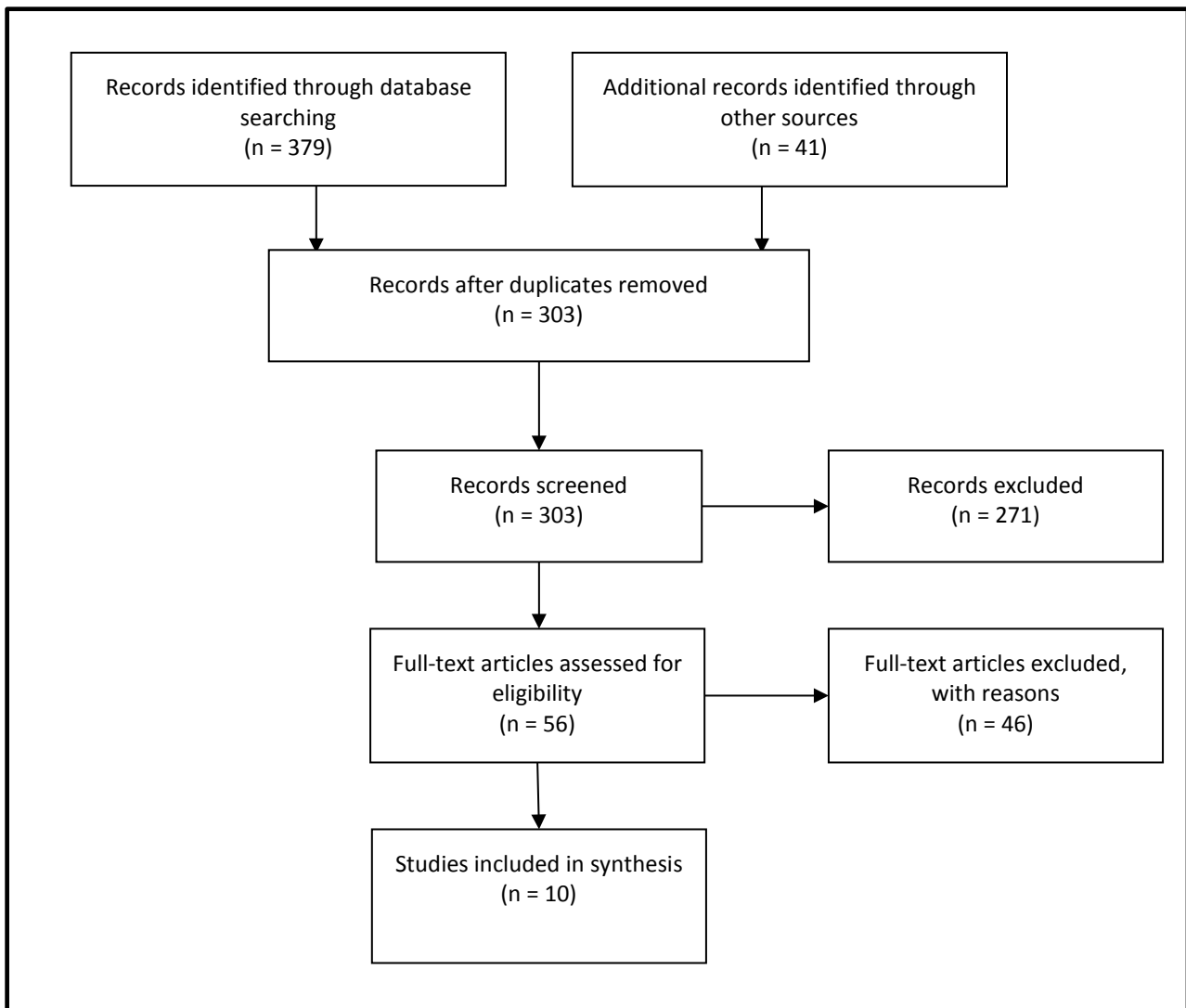


Figure 1. PRISMA flow diagram for articles identified through database searches

Table 1. Participant characteristics

Studies	Individuals with ABI	Age (Mean)	Gender	Injury Type ABI/TBI	Time post injury (Mean)	Functional level	Caregiver Relationship (parent/spouse/children/sibling/other)	Caregiver Age (Mean)	Caregiver Gender
Arco & Bishop ⁴²	1	43	M	ABI	8 years	-	Parents	-	M=1 F=1
Carnevale ⁴⁴	11	30.5	M=7 F=4	TBI	10.2 years	Mean coma duration in weeks = 5.8	Family Members/Caregivers	-	-
Carnevale et al. ³⁹	37	40.5	M=28 F=9	24=TBI 13=ABI	7.6 years	Duration of unconsciousness <24h = 2 >24h = 34 Never unconscious = 1	Family Members/Caregivers	-	-
Carnevale et al. ⁴⁰	27 (Undisclosed overlapping sample ³⁹)	38.9	M=18 F=9	TBI = 17 ABI = 10	8.7 years	Duration of unconsciousness <24h = 1 >24h = 26	Family Members/Caregivers	47.5	-
McKinlay & Hickox ⁴⁵	2	40.5	M=1 F=1	Not specified	2.4 years	1.5wks (PTA*)	Spouse (F) = 1 Adult Son =1	-	-
Palmisano & Arco ⁴¹	3	33	M=3	ABI	3.3 years	DRS [†] Score = 3 (Partial disability) DRS Score = 5 (Moderate disability) DRS Score = 3 (Partial disability)	Spouses	28.3	F
Sander et al. ³⁶	15	22	M=10 F=5	TBI	-	Severe = 10 (GCS [‡] Score ≤ 8) Moderate = 3 (GCS Score 9-12) Complicated mild = 2 (GCS Score 13-15)	Parent= 11 Spouse=3 Other=1	45	M=3 F=12
Wade et al. ³⁷	9	15.04	M=5 F=4	TBI	9.7 months	Severe=2 (GCS Score ≤ 8) Moderate=7 (GCS Score 9-12)	Parents	-	-
Wade et al. ³⁸	9 (Overlapping sample ³⁷)	15.04	M=5 F=4	TBI	9.7 months	Severe=2 (GCS Score ≤ 8) Moderate=7 (GCS Score 9-12)	Parents	-	-
Whiting et al. ⁴³	7	(between 18-62)	M=4 F=3	PBT§	-	-	Spouses = 5 Adult children = 2	45.8	M=4 F=3

Total	112	31.7	M=77 F=35	ABI=24 TBI=95	5.7 years¶		Parents = 21 Spouses = 12 Adult children = 3 Other/not specified = 76	45.4 (n=45)¶	M=8 F=19 (n=26)¶
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* Primary Brain Tumor

† Disability Rating Scale

‡ Glasgow Coma Scale

§ Primary Brain Tumor

¶ Information not provided in all studies

Table 2. PEDro Scale - Critical Appraisal Tool

Criteria (PEDro Scale) – RCT designs	Carnevale et al. ⁴⁰	Carnevale et al. ³⁹
1. Eligibility criteria were specified	Y	Y
1. Subjects were randomly allocated to groups	Y	Y
3. Allocation was concealed	N	Y
4. The groups were similar at baseline regarding the most important prognostic indicators	Y	Y
5. There was blinding of all subjects	N	Y
6. There was blinding of all therapists who administered the therapy	N	N
7. There was blinding of all assessors who measured at least one key outcome	N	N
8. Measures of at least one key outcome were obtained from more than 85% of the subjects initially allocated to groups	Y	Y
9. All subjects for whom outcome measures were available received the treatment or control condition as allocated or, data for at least one key outcome was analysed by “intention to treat”	Y	Y
10. The results of between-group statistical comparisons are reported for at least one key outcome	Y	Y
11. The study provides both point measures and measures of variability for at least one key outcome	Y	Y
TOTAL SCORE	6/10	8/10

Table 3. McMaster University: Critical Review Form – Quantitative Studies³¹

Criteria (McMaster University – Critical Review Form)	Arco & Bishop ⁴²	Carnevale ⁴⁴	McKinlay & Hickox ⁴⁵	Palmisano & Arco ⁴¹	Sander et al. ³⁶	Wade et al. ³⁷	Wade et al. ³⁸	Whiting et al. ⁴³
1. Was the purpose clearly stated	Y	Y	Y	Y	Y	Y	Y	Y
2. Was relevant background literature reviewed	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the sample described in detail	Y	N	Y	Y	Y	N	N	Y
4. Was sample size justified	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
5. Were outcome measures reliable	N	N	N	N	Y	Y	Y	N
6. Were outcome measures valid	Y	N	N	N	Y	Y	Y	N
7. Intervention was described in detail	Y	Y	N	Y	Y	Y	Y	Y
8. Contamination was avoided	N/A	N	N/A	N/A	N/A	N/A	N/A	N/A
9. Cointervention was avoided	N	N	N	N	N	N	N	N
10. results were reported in terms of statistical significance	N	Y	N	Y	Y	Y	Y	N
11. Were the analysis method(s) appropriate	N	Y	N	Y	Y	Y	Y	Y
12. Clinical importance was reported	Y	Y	Y	Y	N	Y	Y	N
13. Drop-outs were reported	Y	Y	N	N/A	Y	Y	Y	Y
14. Conclusions were appropriate given study methods and results	N	Y	Y	Y	Y	Y	Y	Y
TOTAL SCORE*	8/12	7/12	5/12	8/10	10/12	10/12	10/12	7/12

*Although this tool consists of 14 criteria, not all criteria are relevant to each study design. Where this is the case, the criterion is marked as 'not applicable' (N/A)

Table 4. Overview of studies included in review

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Arco & Bishop ⁴² (Single Case Design) [III-3(7/12)]	N=1 Individual with ABI and his caregivers (parents) Male, Age: 43yrs	Location: Perth Setting: Home-based Facilitator: Research Assistant	Observation of target behaviours using task analysis checklist	Parents trained to prompt individual with ABI to self-record behaviors and provide verbal & physical prompts throughout morning routine: preparing breakfast (PB), sitting at dining room table (SDT), eating breakfast (EB).	Mixed and inconclusive. Independent behaviour across the three routines varied PB: <i>M</i> =97% (baseline) <i>M</i> =98% SDT: <i>M</i> =80% (baseline) <i>M</i> =66% EB: <i>M</i> =52% (baseline) <i>M</i> =91%
Carnevale ⁴⁴ (Single Case Design) [III-3(8/12)]	N=11 Individuals with TBI & their families/caregivers M= 7 F=4 Mean age (years): 30.5 Mean age at injury: 20.3	Location: New Jersey Setting: home-based Facilitator: Masters level rehabilitation counselor & behaviour technician	Structured Interviews, Percentage change from baseline data, Attitudinal survey & symptom checklist	Educational module presented in 2 parts: Overview of common neurobehavioral sequelae of TBI, & General principals of behaviour management. Frequency of staff contact was gradually decreased. Follow-up sessions 1,3,6 & 12 month intervals	Significant improvement in target behaviours (82%). Greatest improvement occurring during educational phased. Caregivers felt program information was practical, reasonably paced, & assisted them in coping with daily stressors
Carnevale et al. ³⁹ (RCT) [II(8/10)]	N=37 Individuals with ABI & their caregivers (24=TBI) M=28 F=9 Mean age (years)=40.5 Mean time post-injury=7.6	Location: New Jersey Setting: home & community settings Facilitator: 2 clinical psychologists & a behaviour technician	Observation of target behaviours. Subscale in Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members QRS. Adapted version of Maslach Burnout Inventory (MBI). The Neurobehavioral Functioning Inventory Revised (NFI-R)	Natural Setting Behavior Management (NSBM) Education and individualised behaviour program, versus education only versus control group. Data collection at 7 wks, 16wks & 30 Wks post baseline	Statistically significant improvements in target behaviours at 3-months follow-up ($P<.002$). Significant group differences at 30-week follow-up ($P=.05$).

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Carnevale et al. ⁴⁰ (RCT) [II(6/10)]	N = 27 Individuals with ABI & their families/ caregivers (17=TBI) M= 18 F=9 Mean age (years): 38.9 TPI: 8.7 Caregivers mean age: 47.5	Location: New Jersey Setting: home & community settings Facilitator: Clinical psychologist and behaviour technician, supervised by an experienced neuropsychologist	Subscales of the QRS Adapted version of the MBI	Education only & education plus group met with NSBM staff for approx. 2 hrs wkly for 4 weeks. Education regarding common neurobehavioural sequelae of BI and practical behavior management techniques from a standard protocol. Education plus intervention group met with NSBM staff 2 hrs weekly for additional 8 wks & individualised treatment plans developed. Data collection at 5wks and 14 wks post baseline.	No statistical significance seen for all QRS subscales post intervention. MBI subscales also not statistically significant. In every ANCOVA, the covariate was statistically significant (P< .05), except for QRS subscale 11 (Personal Burden and Respondent) at 14 wks post baseline (P= .052). Indicates that initial baseline level on these subscales was highly predictive of outcome.
McKinlay & Hickox ⁴⁵ (Single Case Design) [III-3(5/12)]	N=2 Male, Age: 41yrs TPI: 4 yrs PTA: 1 wk Case 4 Female, Age: 40 TPI: 9 months PTA: 2 wks	Location: UK Setting: Community-based Facilitator: not identified	Frequency counts of temper outbursts	Triggers of temper outbursts are identified. The relative prompted and rehearsed management strategies with participant, including anticipating trigger, going through 'temper routine' & recording event. Acceptable assertiveness behaviours are also taught, & relatives provided with info about handling stressful situations & their response to participant's problems Treatment period 19wks	Significant improvement seen in Case 4, with no temper outbursts reported in second half of treatment. Case 3 revealed no convincing improvements.

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Palmisano & Arco ⁴¹ (Single Case Design) [[III-3]8/11]	N=3 (Males) Individuals with BI & their spouses Participant 1 = 44 yrs, caregiver 28yrs. Participant 2: 25yrs, caregiver 28yrs. Participant 3: 30 yrs, caregiver 29yrs.	Location: Perth Setting: Home-based Facilitator: Researcher	Observations of task behaviour using task-analysis checklist Questionnaire of Resources and Stress – Short Form (QRS-SF). Purpose-designed questionnaire to measure social validity Length of intervention: 6 weeks.	Spouses trained to use checklists to record target behaviours. Development of individualised intervention plans reviewed during alternative weekly 1-hr home visits. Follow-up 1 month post intervention	Significant improvement of target behaviour (P1 – 60% to 97%)(P2 – 62%-90%)(P3 – 60%-90%). No significant change in caregiver burden.
Sander et al. ³⁶ (Single Case Design, Feasibility study) [III-3(10/12)]	N=15 Caregivers of individuals with TBI Mean age (years): 22 M = 10 F = 5 Severe TBI = 10 Moderate TBI = 3 Complicated mild TBI = 2 Caregiver mean age: 45 F= 12 M = 3	Location: West Texas Setting: Community-based Facilitator: post-doctoral fellow in neuropsychology, & a master's-level counselor (developed content). Information presented by 2 neuropsychologists	Problem checklist (PCL) from the Head Injury Family Interview (HIFI) Supervision Rating Scale (SRS) Perceived Burden subscale of the Modified Caregiver Appraisal Scale (MCAS) Satisfaction survey Follow-up Interview	6 web-based videoconference sessions using PowerPoint (15-20 mins). Didactic education & interactive problem-solving. Number of sessions attended dependent on caregiver needs. Data collection within 2 weeks of discharge from trauma centre 9 caregivers completed follow-up interviews average 18mths post-intervention	Significant findings with regard to caregiver satisfaction. For each module participants rated satisfaction as 'very satisfied' or 'somewhat satisfied'. Majority participants reported amount of information presented was 'just right'. Some felt not enough info on general education, awareness, attention & memory

Study (design) [level of evidence]	Sample Characteristics	Delivery	Outcome Measures	Intervention	Findings
Wade et al. ³⁷ (Single Case Design) [III-3(10/12)]	N = 9 Adolescents with TBI and their families M= 5 F=4 Mean age (years): 15.04 (range: 11:8-18: 2) Mean time post injury: 9.7 months (3-21 months) 2= Severe TBI 7= Moderate TBI	Location: Ohio Setting: Home-based videoconferences Facilitator: 3 licensed psychologists	Website Evaluation Questionnaire (WEQ) Adapted version of the Online Satisfaction Survey (OSS, parent and teen versions) Completed by 7 mothers, 5 fathers & 9 adolescents at postintervention follow-up (average 11 days after completing final session [range 0-27 days]).	Teen Online Problem Solving intervention (TOPS). Ten core sessions including information about TBI, problem solving, organizational skills, coping with behavioural changes, & planning. 4 additional sessions offered based on skills, therapist recommendations and interest. Baseline & postintervention follow up (average 11 days after final session was completed).	Significant findings with regard to caregiver satisfaction and increased knowledge. Participants rated the helpfulness and ease of use of website & videoconferences as moderate to high. Both parents and adolescents reported increased knowledge and skill.
Wade et al. ³⁸ (Single Case Design + control group) [III-3(10/12)]	N=9 Adolescents with TBI M= 5 F=4 Mean age (years): 15.04 (range: 11:8-18: 2) Mean time post injury: 9.7 months (3-21 months) 2= Severe TBI 7= Moderate TBI	Location: Ohio Setting: Home-based videoconferences Facilitator: 3 doctoral-level clinical psychologists	The child Behavior Checklist (CBCL) Children's Depression Inventory The Global Severity Index of the Symptom Checklist 90-R Short form of Conflict Behavior Questionnaire (CBQ) The issues checklist and Issues Severity Scale	Families randomly assigned to TOPS (web-based problem-solving treatment programs for adolescents with TBI and families) with or without audio. 5 families – TOPS-audio 4 Families – TOPS-no-audio TOPS consisted of 16 sessions. Ten sessions – problem-solving, communication & social skills training. Self-assessment completed following ninth session. 4 supplementary sessions offered based on needs & interest	Parents reported significantly fewer internalizing symptoms at follow up ($P=.03$). Adolescents & parents reported lower levels of depression. Parents reported significant reduction in parent-adolescent conflict ($P=.04$) and problem issues ($P=.01$). Participants in TOPS-audio group had greater outcome in some areas.

Whiting et al. ⁴³ (Pre – Post test Mixed-Methods Design) [III-3(7/12)]	N=7 Caregiver & family member with Primary Brain Tumour (PBT) M = 4 F = 3 (between 18-62 yrs) Caregiver: Spouse=5 Adult children=2	Location: Sydney Setting: Training session based on knowledge of home- based interactions Facilitator: Radiation Oncologist, Neurosurgical clinical Nurse Consultant & Clinical Psychologist	The Strategy Use Measure (SUM) – purpose-developed. 9-item scale to evaluate use & knowledge of compensatory strategies to manage behavioural & cognitive changes Purpose-designed evaluation questionnaire	3.5 hour workshop comprised of 5 sessions, included education & group discussion	Family participants demonstrated significant increase in knowledge postintervention (P<0.05) Participants rated workshop to be 'good' and 'very good' with open-ended items reflecting increased knowledge.
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