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Traumatic Brain Injury Education for Adult Patients and Families: A Scoping Review

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Abstract

Traumatic brain injury (TBI) is increasingly viewed as a chronic condition, bringing long-term needs for patient and caregiver knowledge pertaining to symptom and problem management over time. In light of these needs, we performed a scoping review of the literature on brain injury education provided to adult patients and/ or family members affected by TBI. Objectives were to describe the types of educational interventions that have been developed; to review the effects of these interventions; and to determine gaps that might be filled by future research efforts. Of 88 articles meeting search criteria and subjected to data extraction, 34 concerned education about mild TBI and 54, moderate to severe TBI. Most mild TBI articles focused on education in the

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Emergency Room, while most moderate/ severe TBI education was directed toward family members/ caregivers and was frequently combined with other treatment components, making the effects of education difficult to discern. Only 1 article incorporated elements of self-management training (SMT), a model proved effective in other chronic health conditions. We recommend further exploration of SMT principles in long-term TBI care, as well as more precise definition of treatment components in all patient and family interventions, so that the specific effects of education and other treatment elements may be more readily evaluated.

Keywords

Brain injuries; patient education; family education; self-management

Introduction

Traumatic brain injury (TBI) is a major health problem affecting thousands of people annually in the US, with adverse effects on physical, cognitive, behavioural and emotional function. Moderate to severe TBI is accompanied by reduced participation in many spheres of life, including low rates of work or other productive activity and reduced social and recreational outlets (1). Mental health difficulties such as depression, anxiety, and anger/ irritability are common and persistent, and there is significant deleterious impact on overall quality of life (2). Family stress and burden are also common as the family system adapts to changed roles, ongoing care and supervision needs, and financial strain (3). Even so-called minor or uncomplicated mild TBI (mTBI), although followed by full recovery in the majority of cases, may result in persistent cognitive, physical, and emotional sequelae (4). The consequences of mTBI have attracted increased attention due to the debilitating problems experienced by many service members and Veterans, which are often comingled with symptoms of post-traumatic stress and chronic pain (5).

In the case of moderate/ severe TBI, it was once thought that the injury was a 'one-and-done' event, followed by recovery that would reach a permanent plateau within a year or two. Longitudinal studies have shown, however, that TBI may set off a dynamic process characterised by fluctuations in functional status over the lifespan (6). Thus instead of a static disability, TBI may best be treated as a *chronic condition*, with ongoing management and support provided to prevent deterioration and maximise recovery. However, the ideal components of long-term management for TBI have yet to be identified.

In other chronic health conditions such as diabetes, asthma, and heart disease, much research has focused on designing and testing the optimal ways of helping affected persons to understand and manage the consequences of the condition. Patient education is a key component of chronic disease management, with decades of research examining the effects of different kinds of information and guidance on symptom management. As one example, an instructional model known as neuroscience education (NE) has gained increasing use in the management of chronic pain. Rather than focusing on the anatomical or biomechanical aspects of pain, which can exacerbate anxiety, NE teaches patients about the way pain is processed within the nervous system, emphasises that physical activity can be helpful rather

than harmful, and shows patients how to influence their own experiences of pain. A systematic review found compelling evidence that this kind of information, even when administered in brief sessions, reduces the perception of both acute and chronic pain and limits pain catastrophizing (7). Another highly influential model that includes patient education at its core is Self-Management Training (SMT), developed by Lorig and colleagues and used extensively for chronic disease management (8). SMT goes beyond the provision of information to include peer-led training in problem-solving and goal-setting related to chronic symptom management, as well as how to best make use of one's healthcare resources.

If we reconceptualise TBI as a chronic health condition, it is timely to ask whether and how patient education, perhaps including components of SMT, could help people with TBI to manage the long-term consequences of the disability. There appears to be great consumer demand: studies assessing the perceived needs of people with TBI and their caregivers have consistently identified as paramount the need for accurate, understandable information about the injury and its potential consequences (3, 9, 10). Family caregivers, in particular, have expressed concern that 'they did not know what they did not know' to help the injured person maximise recovery (3, 11). It has also been noted that most studies of information about TBI have focused on the acute phase of recovery, and that empirical studies of the effects of different models of patient/ family education are almost nonexistent (12).

Considering the importance of this topic, in view of the expressed needs of people with TBI and their caregivers and the growing recognition of TBI as a chronic health condition, we conducted a scoping review to examine the literature on TBI education provided to patients and family caregivers. Unlike a systematic review, in which the quality of the research is considered with the goal of evidence synthesis, a scoping review surveys the overall scope of published work on a particular topic toward the goal of identifying key concepts and gaps in the extant literature (13). In this review we sought to address the following questions:

1. What does the published literature reveal about the kind of education provided to patients and family members/ caregivers about the consequences of TBI?
 - a. Have different, distinct models of education been developed for this population?
 - b. What effects, if any, have been reported for different types of educational interventions?
 - c. Is there a sufficient number of empirical studies to warrant a systematic review or meta-analysis?
2. What are the gaps in the literature relative to the above questions, and how might they inform priorities for future research in this area?

Method

We conducted systematic searches for peer-reviewed articles published in English about the education and training of persons with TBI and their caregivers. Searches included studies using all designs, including meta-analyses and literature reviews. The databases searched

were PubMed, CINAHL, PsycINFO, Cochrane Library, ABIEBR, Campbell Library, PROSPERO, and PsycBITE. Searches were performed using the appropriate subject heading terms and key words for TBI, head injury, concussion, and education, training, and instruction. Complete search strategies for each database, including all search terms used, are provided in Appendix A. The searches were completed on October 27, 2016 and yielded 3,209 unique titles.

We reviewed all abstracts to determine eligibility for inclusion according to three criteria: (1) published in English, (2) published in peer reviewed journals, and (3) involved education or information or training (including self-management training) given to patients or families about the consequences of TBI. Articles on other etiologies of acquired brain injury were included, as long as TBI was included as a topic or as part of a study sample. Because our main interest was in comprehensive brain injury education, we excluded articles that concerned the training of one specific or circumscribed skill such as wheelchair mobility, anger management, goal management, etc. However, we did include articles about programmes that systematically covered many individual topics in an educational format, e.g. the specific physical, cognitive, and behavioural consequences of TBI, as coverage of multiple topics was felt to constitute comprehensive education. We excluded non-peer-reviewed pieces such as editorials and letters to the Editor, as well as articles intended for audiences such as coaches, educators, or the general public. We also excluded articles that made only brief mention of education (e.g. a programme description that noted merely that 'education was included') with no further details.

We reviewed the full text of all articles that met these criteria. Articles that did not have an abstract or did not provide sufficient information to determine eligibility were automatically included for full-text review. All abstracts and full text articles were reviewed by at least two independent reviewers. Disagreements were resolved by discussion and, if necessary, by asking a third reviewer to break the tie. Data from eligible studies were extracted on variables related to: a) characteristics of the sample or intended audience of the education (e.g. severity and chronicity of TBI; age; intended for patient, family, or both); b) type of report (e.g. descriptive, experimental); c) the content, method of delivery, and duration of the TBI education; and d) results or author conclusions with regard to the education.

Figure 1 provides detail on the abstract and full text review process. As shown in the Figure, 117 articles were determined to be eligible for data analysis. Twenty-nine of these papers concerned pediatric TBI/ ABI and were quite different in focus than the papers on education for adults. We therefore elected to use the 88 papers focused on adult patient/ family education for the current manuscript.

Results

When data had been extracted from all included articles, the study team examined the distributions of key variables to determine how the findings should be organised. We elected to group findings by severity of injury (mild versus moderate/ severe) on the grounds that educational interventions targeting these cohorts would be quite different, as well as likely to be delivered in different service settings. Severity of injury was generally inferred in one of

two ways. Some articles were readily classified by the title alone (e.g., “Information provision after mild traumatic brain injury”) or the contents of the title plus abstract. Others, particularly manuscripts reporting the results of studies, were classified on the basis of information provided on the study samples. In these cases, we used data on commonly used indices of TBI severity (admission Glasgow Coma Scale scores, duration of loss of consciousness, duration of post-traumatic amnesia, and/ or neuroimaging findings) to classify articles as concerning either mild or moderate/ severe TBI. If articles included both participants with mTBI and moderate/ severe TBI, we included them in the moderate/ severe group unless participants with mTBI predominated in the sample and the content of the article was consistent with mTBI. One experimental article (14) did not identify the severity of the sample but appeared to be more germane to mild injury and was included in that group. Thirty-four articles concerned mTBI, and 54 focused on moderate/ severe injury.

Table 1 presents an overview of the studies included in this review. As shown in the Table, there has been an increase in manuscripts concerning TBI education over time, particularly in the case of mTBI since 2010. The Table also reveals that educational efforts for mTBI have tended to target the injured individuals and to be focused on traumatic injury, while moderate and severe TBI education is more likely to target or include families and caregivers, and to include both traumatic and non-traumatic injury. Regarding timing of education, mTBI papers are more likely than those concerning moderate/ severe injury to include information intended for those in emergency care. The majority of manuscripts in both groups have discussed in-person education, as opposed to phone or web delivery. Group interventions that include education are proportionally more common for moderate/ severe than for mild injury.

Mild TBI

Mild TBI education provided in emergency care.

Considerable attention has been devoted to examining the types of educational materials (i.e. discharge instructions) supplied to patients and caregivers admitted to emergency care with mTBI. Survey studies focused on collecting and comparing such materials from regional hospitals have been conducted in the United States and Canada (15), England (16), Australia (17), Scotland (18), and New Zealand (19). These reports have emphasised the wide variability in the content provided to patients with mTBI and have called for more uniform, more accurate, and easier-to-read materials. The span over which these papers have appeared—1997 to 2014—suggests that the need for such materials may remain unmet.

Several empirical studies have examined the conditions under which patients receive mTBI-related education in emergency care, as well as patients’ or caregivers’ comprehension or memory for various kinds of discharge instructions. One study found that education about mTBI was more frequently provided when a diagnostic code of ‘concussion’ was used relative to codes of motor vehicle collision (MVC) or whiplash, even though more people with the MVC diagnosis reported symptoms consistent with mTBI (20). In two studies, patients with mTBI were interviewed after emergency discharge and queried about the discharge instructions they had received. Both found that many patients did not recall having been given instructions even when they had (21, 22). Memory for instructions was

inconsistent, and worse for those with longer periods of post-traumatic amnesia (21). A non-randomised controlled study found that instructions given in the Emergency Department to patients with mTBI were understood and recalled better after 48 hours when verbal instruction was given along with written material, compared to written material alone (23).

Descriptions of mTBI education beyond emergency care.

Eight papers were classified as descriptive reports concerning mTBI education outside of emergency care. One small qualitative investigation focused on the perceptions of benefit related to a treatment programme for persistent post-concussive symptoms that included not only education but stress management training and compensatory strategy development (24). A survey of primarily American neuropsychologists in 1994 revealed that education was the intervention most often used (endorsed by 82% of respondents) for patients with 'post-concussive syndrome' (i.e. symptomatic mTBI). Moreover, those who used educational approaches also rated treatment for mTBI as more successful overall (25).

The remaining six papers were descriptions of treatment models for mTBI that included education; one offered a written educational guide that could be copied and offered to patients (26). Three were early (1980's to 1990's) descriptions of treatment approaches (27–29). The two more recent papers emphasised the use of a biopsychosocial model to address the complexities of symptomatic mTBI, and both stressed the importance of keeping up with the burgeoning mTBI literature so that patient education and other treatment would continue to be evidence-based (30, 31). The purpose of education in such programmes was described as helping to prevent misattribution of everyday cognitive slips to the TBI, and to prevent catastrophizing symptoms.

Effects of mTBI education on patient/ family outcomes.

Eight randomised controlled trials (RCTs) examined the effects of education on various outcomes of mTBI. Two used a group educational series as a control for a reasoning skills intervention, with results that were non-contributory for our purposes (14, 32). Similarly, another study used education in the form of an information manual to control for nonspecific effects of various forms of cognitive and psychotherapeutic rehabilitation, in a military sample with chronic post-concussive symptoms (33.) As hypothesised, the education condition had no significant impact on change in cognitive or functional status. However, an earlier RCT with 3- and 12-month follow-up in a civilian sample (34, 35) showed that a brief educational intervention was equally effective for ameliorating post-concussive symptoms, compared to a more intensive treatment programme that included neuropsychological evaluation with feedback, a Physical Therapy consultation, and treatment sessions as needed. A slightly more intensive early intervention, 4–5 telephone contacts to provide education and counseling over the first 3 months after mTBI, also resulted in fewer symptoms and less impact of symptoms at 6 months post injury (36). These contrasting findings are likely due to differences in selection criteria: the civilian samples were drawn from consecutive admissions to emergency wards, many of whom would be expected to recover over the period of time that the education was administered. In contrast, the military sample consisted of persons with chronic symptoms for which they actively sought treatment; this sample likely also had a higher rate of comorbidities such as post-traumatic

stress. Another intervention for Veterans with remote mTBI (mean 10 years post injury) and chronic problems led to improvement in community integration (37) and diminution in caregiver burden (38) when compared to usual care. This intervention included home visits as well as telephone contacts over a 4-month period, and used a variety of treatment approaches, such as goal setting and action planning, in addition to education.

Two RCTs examined the effects of education delivered remotely to persons with mTBI. Belanger and colleagues (39) compared a brief (10–45 minute) web-based educational module to usual care in Veterans with chronic symptomatic mTBI. Although a previous pilot study had suggested benefit (40), little change was observed in the RCT. However, subgroup analyses showed greater benefit in those who were involved in mental health treatment, suggesting that education could serve as a useful adjuvant intervention. Moreover, participants who showed greater learning of the presented information also improved more on a measure of self-efficacy, i.e. perceived control over symptom management (39). The other remote intervention was an RCT using symptom assessment delivered 3 times daily for 14 days via SMS (text messages), starting on the day of injury. Half of the participants also received follow-up texts offering reassurance, education, and guidance contingent on their symptom reports. These educational messages appeared to be effective in preventing or reducing anxiety and irritability, although there was low power to detect group differences in this small pilot trial (41). Importantly, the SMS-delivered intervention was shown to be feasible and well tolerated in persons with acute mTBI.

A study using non-randomised cohorts suggested that a brief in-person intervention that included education, reassurance, and guidance on reducing alcohol intake resulted in less use of alcohol 3 months after mTBI compared to usual care (42). An uncontrolled, retrospective study reported beneficial effects of an 8-week programme involving in-home treatments from an Occupational Therapist and educational phone sessions with a psychologist for a group of patients who mostly had chronic mTBI (43). However, results are difficult to interpret due not only to the absence of controls but to the high proportion of participants receiving or seeking injury compensation (>50%). Two treatment models were described with pre- and post-test data suggesting improvement in emotional well-being, but without controls. One was a group treatment for Hispanic patients with chronic, predominantly mTBI that included education, relaxation training, and goal setting (44). The other was an adaptation of the Multi-Family Group Therapy model, a lengthy treatment (9–18 months) originally developed as a group co-treatment for patients and family members affected by serious mental illness. The adapted treatment, developed for a military sample with mTBI, included educational workshops and written materials on TBI and post-traumatic stress, as well as on the health benefits of positive thinking and active problem-solving. A stated purpose of the education is to help normalise the stress experienced throughout the family, particularly in the marital relationship (45). Results of an uncontrolled pre-post study suggested improvement in coping with anger, improved social support and productive activity, and decreased caregiver burden. Of note, cognitive impairment at baseline was predictive of less treatment response (46, 47).

Moderate/ severe TBI

Descriptions of moderate/ severe TBI education.

About 40% (n=22) of the moderate/ severe articles were descriptive reports, often quite brief, of programmes that included family (more rarely, family + patient) education without evaluative data. Nine of these were published in the 1980s or 1990s (48–56), when specialty TBI programmes were relatively new; thus the purpose of such papers appeared to be the sharing of ideas and models for assisting family members to understand and cope with the injury. While undoubtedly useful at the time, these articles may now have limited utility; for example, one suggests the practice of videotaping to supplement discharge instructions (56), which is now commonplace. Others included bibliographies (52, 53), now outdated, that were intended to be shared with patients or family members.

Three papers published since 2000 were, similarly, descriptions of specific programmes (57–59). However, some of the more recent papers provide illustrations of interesting trends. Several papers published since 2000 have described the incorporation of user input or feedback to develop and/ or evaluate the quality of TBI education (60–63). A case report described the use of telehealth, including streamed video, to provide remote education and other services to families with restricted access to specialized care (64). Two papers described the development of TBI education and support services to meet the needs of specific communities, one in the United Kingdom (65) and the other in South Africa (66).

Three additional papers were concerned with detailing the services provided to people affected by TBI, including education, although each followed a different approach. King et al. (67) described the interventions used in the treatment arm of a large stepped-care trial of education and advice given to patients with TBI during the 6 months postinjury. Not surprisingly, the need for advice and referral for services, in addition to education, was found to be greater for those with more severe TBI. These authors recommended that brief information leaflets, of the type used in their trial, should not be provided without the opportunity of contact with an interventionist to help explain the information and offer individual advice. Short and colleagues (68) described results of an online survey completed by Speech-Language Pathologists in Australia regarding information given to patients with TBI about their cognitive-communication deficits. These authors similarly found that severity of TBI was a common consideration, along with awareness of deficits, guiding the decision as to who should receive factual information (e.g. patient versus caregiver) and when. Finally, Simpson et al. (69) conducted an observational study to ascertain the types and relative proportions of Social Work services provided in an inpatient rehabilitation setting for severe TBI. Education/ information was the largest service category, accounting for 23% of direct care hours.

Multi-component interventions for moderate/ severe TBI.

In contrast to the papers on mTBI, the moderate/ severe TBI group included a large number of papers (n = 20) that described interventions *containing* education on brain injury among other components of intervention targeting families/ caregivers, patients, or both. These papers described the findings of experimental or, more often, quasi-experimental studies

such as pre-post-test or non-randomised control group designs. They were very diverse with regard to inclusion of participants with TBI only vs. other types of acquired brain injury; mode of delivery (in person, telephone, web; individual vs. group); and the duration and intensity of treatment. The components of intervention added to education were also quite diverse but frequently included emotional support, counseling, or psychotherapy; coping skills training; goal-setting; provision of community resources; and individualised advice. One included sessions focused on topics related specifically to self-management, such as 'How I look after myself,' 'How I work with services,' and 'How I live in the community' (70). Befitting these broad interventions, there were typically a variety of outcome domains measured, e.g. emotional function, family function, coping, caregiver burden, and individualised goal attainment. In such reports, it was not possible to examine quantitatively the specific effects of education; however, some of the papers included either author inferences or participants' comments on the effectiveness of the information or education components. Thirteen papers did not include any comments on education (71–83). The other 7 mentioned the value of education for filling knowledge gaps or correcting misinformation (84), for understanding the point of view of others dealing with brain injury, specifically relating to injured persons developing empathy for family members (85), and for increasing one's confidence in dealing with problems at home (86). Specific education topics that were reportedly most valuable for caregivers included cognitive and behavioural issues, such as memory impairments and impaired self-awareness (86, 87). Negative aspects of education included information presented in too technical a fashion to be accessible to family members or patients (84), and lack of use of presented information. For example, one web-based intervention found that family members preferred an on-line support group function to a variety of educational resources, which were seldom used (88). Authors of an RCT on family education and problem-solving reported that many participants did not read the written materials that were prepared to support each session (89).

Effects of moderate/ severe TBI education on patient/ family outcomes.

Six studies were explicitly designed to test the specific effects of education, including 3 RCTs. A study published in 1987 (90) compared standard caregiver instructions for discharge from an acute neurosurgical ward (which at the time explained mostly physical symptoms such as poor coordination or weakness) with instructions that included detailed explanations of cognitive/ behavioural symptoms such as lack of initiative, self-centredness, and decreased learning ability. Immediately after receiving their randomly assigned instructions, caregivers received vignettes depicting various problems at home and asking how they would handle each; caregivers receiving the more comprehensive education scored significantly higher on the quiz. A more elaborate educational programme, comprising 8 2.5-hour sessions, focused on written and oral didactic information presented separately to groups of people with chronic TBI and groups of caregivers. Compared to waitlisted controls, patient participants improved more on measures of emotional function and self-esteem, but caregivers showed no significant benefits (91). In the third RCT, Pegg and colleagues (92) compared two types of education delivered to patients with TBI on an inpatient rehabilitation unit. Those who received three 60-minute sessions of individualised education about their injuries, treatment plans, and progress in therapy were rated as putting forth more effort in Physical (but not Speech) Therapy and also achieved more gains on the

Cognitive (but not Motor) FIM, compared to patients randomised to equivalent time spent in a more generic education. The authors speculated that the experimental treatment might have led to a greater sense of control and involvement in rehabilitation, even though it was noted that not all patients completely understood the information.

Two reports on the effects of education were quasi-experimental studies comparing early (2–9 months) versus later (1 year) recipients of caregiver education (93), and attendees versus non-attendees at a family educational series (94). Neither paper reported significant effects on emotional function or family functioning. An uncontrolled pretest-posttest study examined the perceived preparedness of family caregivers for discharge from inpatient rehabilitation, before and after being given access to a website with information and resources. Item analyses showed improved preparedness scores for most domains of caregiving. However, the sample included caregivers of people with mixed diagnoses, and it was noted that the 5 caregivers of patients with brain injury showed the lowest preparedness scores at post-test (95).

As was the case for the mTBI papers, our search turned up a number of RCTs on moderate/severe TBI that employed an educational intervention as a control condition for a diverse set of presumed active treatments. Education alone had no significant positive effect on the outcomes targeted in most of these trials (96–100). However, TBI education was reported as leading to more changes in emotional well-being, confidence, and understanding of TBI-related issues compared to Attention Process Training, which produced more changes in memory and attention, in a small within-subjects trial (101). In another study, ‘instructional counseling’ by a nurse, delivered as a control treatment via weekly telephone contacts, was said to produce results equivalent to in-hospital care for patients randomised to home or hospital within 3 months of TBI. The counseling, however, was individualised and included components other than education, such as problem-solving and suggestions for specific activities and exercises to promote recovery (102).

Discussion

The objective for this review was to assess the scope of the literature on education about TBI delivered to patients and/ or families. We sought an overall perspective on the kinds of education provided, whether distinctive models had been developed and compared, and what effects of education had been reported. One purpose was to determine whether there were sufficient empirical reports to warrant a more detailed or quantitative systematic review. Another was to identify gaps in the research on this topic and provide suggestions for further study.

We found a large variety of interventions that included education about TBI, frequently combined with other treatment elements such as coping skills, problem-solving, and resource facilitation, as well as peer support in group-based interventions. The examples of ‘pure’ education, i.e. delivery of information about TBI and its consequences, were found mostly in the literature on mTBI. Practice surveys and a few empirical reports focused on the information given to patients in emergency care or shortly thereafter, both to alert patients to issues that would need further medical attention and to help them interpret

symptoms. It is logical from a clinical standpoint that interventions for moderate to severe TBI, and for persistent symptoms following mTBI, would incorporate treatment elements other than education; indeed, the number of studies using brain injury education alone as a control condition for an active treatment (n = 10) speak to the expectation that education by itself would be ineffective, at least for the outcomes targeted in those studies. From a research perspective, the descriptions of these multi-faceted programs do not allow for analysis of the effects of specific components of treatment, including the educational content. Regarding the question of distinct models that could be compared head-to-head or subjected to meta-analysis, it appeared that most studies developed educational content and other programme elements *de novo*. Even the examples of similarly named treatments (e.g. Multifamily Group Therapy (45–47)) were quite different in content, intensity, duration, and sample composition. Considering the very wide variety of treatment approaches, we conclude that a more formal systematic review would be premature, and a meta-analytic approach would not be possible.

From a qualitative synthesis of the literature, we offer the following conclusions about brain injury education for patients and families:

1. Interest in mTBI education has risen in the last decade along with increased concern about the potentially serious consequences of repetitive injuries sustained in sports and in battle, and there appears to be consensus that education is a critical element in the treatment of mTBI (25). The rapid accumulation of knowledge about diagnosis and treatment of mTBI creates challenges for keeping education up-to-date (30, 31) and for helping patients separate fact from speculation.
2. Early education on the symptoms and typical recovery course of mTBI may be helpful for reducing symptoms or their impact on daily functioning (34–36). However, in the minority of patients for whom symptoms persist, education may not be effective unless accompanied by other psychotherapeutic treatment components (33). In such cases, a more comprehensive biopsychosocial approach to treatment is warranted (30, 31).
3. The early literature on educational interventions for moderate/ severe TBI was predominated by descriptive reports of specific programmes that were geared mainly to family/ caregivers, rather than persons with TBI. More recently, injured persons have been included in group interventions, either for themselves or along with family members; additionally, there has been a trend toward the use of patient/ family input in developing and refining such programmes (60–63). However, programmes for moderate/ severe TBI are more likely than those for mTBI to include mixed etiologies of brain injury. While this approach may be economical in the clinical setting, it runs the risk of diluting information that could otherwise be of specific help to those with traumatic injuries.
4. The existing literature provides few definitive findings as to the specific effects of education on recipients, other than the proximal outcome of increased knowledge (90). However, confidence in one's ability to handle problems (i.e. self-efficacy)(39, 86, 101) and a greater degree of investment in one's

rehabilitation (92) are two outcomes that have been noted in previous studies and should be explored further, as gains in these areas have the potential to ‘snowball’ into additional improvements in functioning and emotional well-being.

Additional recommendations for future research in this area include the following:

1. For mTBI, there may need to be further development and research devoted to finding the most clinically- and cost-effective ways of delivering early education, not only for flagging problems that should bring patients back to emergency care, but for helping to prevent symptom exacerbation. The scant evidence in the existing literature suggests that the distribution of leaflets should be bolstered by some type of oral instruction or repetition of content (21–23, 67).
2. Remote delivery of interventions including education, via telephone, internet, or text messages, has begun to be tested and will undoubtedly increase. Further study in this area should take note of the somewhat mixed findings to date, which suggest that web-based education may be valuable as a supplement, rather than a replacement, for more traditional delivery methods (39, 40).
3. A problem in this area, which affects rehabilitation treatment research as a whole, is inadequate definition of interventions (103.) Further studies along the lines of Simpson and colleagues (69), which attempted to define and count specific forms of treatment, would ultimately help to enable the identification of the ‘active ingredients’ of TBI education and affiliated treatment models, and would promote replication. The recent use of manualized treatments (77, 85) is a positive trend in this regard.
4. We recommend the exploration of self-management training models for people affected by moderate/ severe TBI, who may need to address a variety of evolving problems for years postinjury. Full-blown SMT (8) has not been applied to this population, likely because cognitive limitations could impede some aspects of the model (e.g. peer leadership). However, our search revealed one attempt to teach SMT-related topics, such as ongoing self-care and wellness and how to communicate effectively with healthcare systems, to people with moderate/ severe chronic brain injury (70). We encourage more such efforts to help injured persons gain maximal control over the impact of their symptoms, even if help from others continues to be needed.

Conclusion

The provision of patient education plays a critical role in the management of chronic diseases such as diabetes and arthritis, yet the role of educational interventions in improving long-term health and quality of life after TBI have not been thoroughly investigated. This scoping review clearly indicates that educational materials and interventions provided to patients and/ or families after TBI vary considerably in content, mode, duration, and intensity of delivery. Nonetheless, there are hints in the literature that providing even basic information can improve patient and caregiver self-efficacy and motivation for rehabilitation

and recovery, and that persons with significant cognitive impairment can participate in self-management training. Given the opportunity for progress in this area of study, we call on clinicians and researchers to identify or develop evidence-based educational content and to develop systematic approaches to delivery of educational interventions along the continuum of TBI care.

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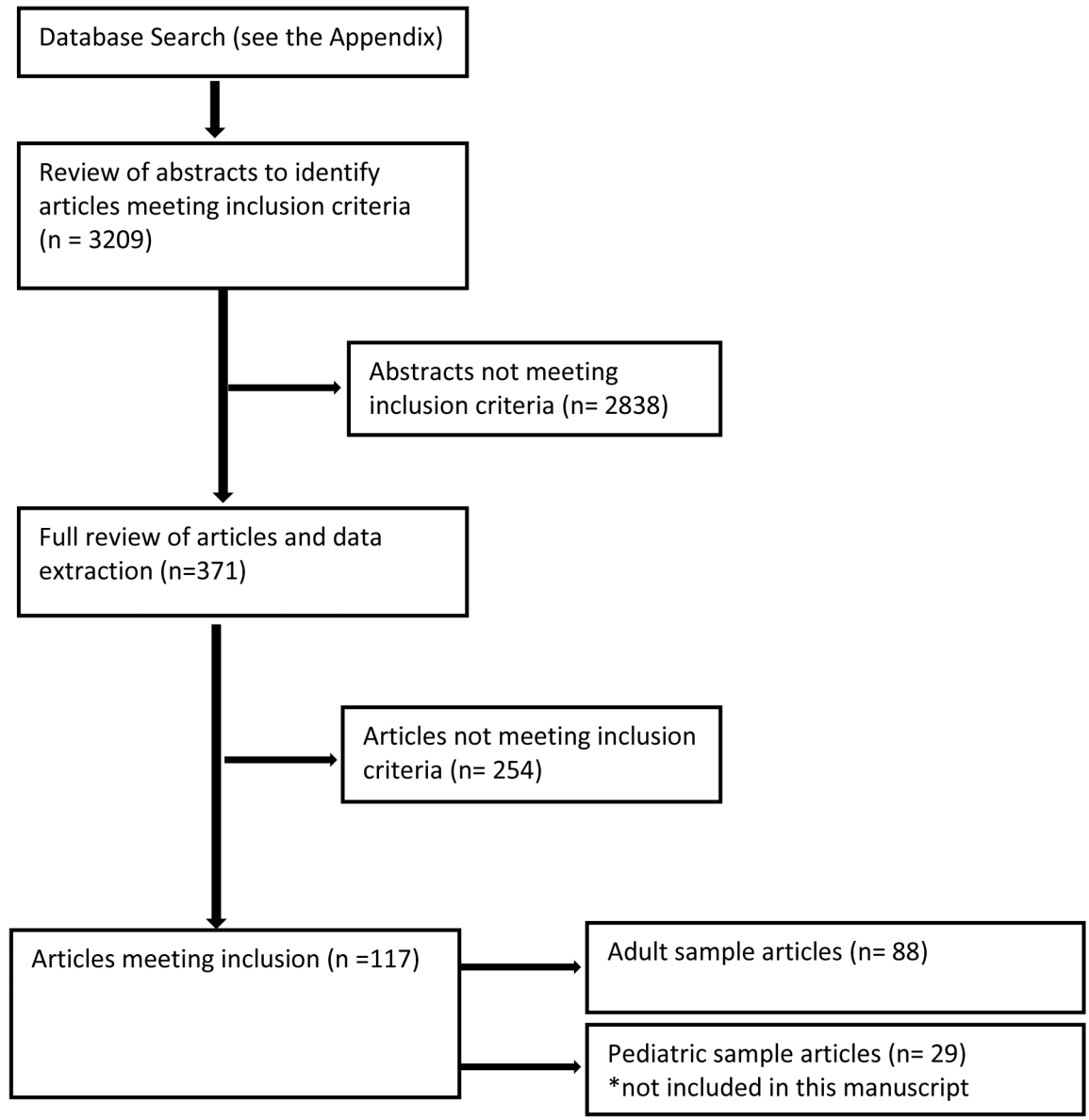


Figure 1:
Study selection flowchart

Table 1.

Selected variables by severity group

	Mild TBI (N=34)	Moderate/Severe TBI (N=54)	Total Sample (N=88)
Publication years			
1980s	2	5	7
1990s	8	10	18
2000s	7	22	29
2010s	17	17	34
Group for whom Education is Intended			
People with TBI	24	9	33
Family/caregivers	2	27	29
Both	8	18	26
Target Population			
TBI specifically	33	32	65
ABI including TBI	1	22	23
Setting/ Chronicity*			
Emergency care	18	2	20
Acute care	4	9	13
Inpatient rehab	0	15	15
Outpatient/ Community	23	43	66
Role of Education			
Sole or main component of intervention	16	19	35
One component of intervention	18	35	53
Education Delivery method*			
In person*	24	40	64
Individual (1:1)	16	24	40
Dyad	3	6	9
Group or class	9	21	30
Telephone	6	12	18
Web	2	5	7

* Note: response categories are not mutually exclusive.

Appendix 1:

Documented Search Protocols

Database	Search Terms
PubMed	(Traumatic brain injur* OR brain injur* OR TBI OR Brain Injuries[mh] OR head injur* OR concussi* OR Brain Concussion[mh] OR Postconcussi* OR Post-concussi* OR Post-Concussion Syndrome[mh]) AND (Educat*[ti] OR "Caregivers/education"[mh] OR "Patients/education"[mh] OR "Family/education"[mh] OR Patient Education as Topic[mh] OR Health Education[mh] OR Consumer Health Information[mh] OR teach*[ti] OR train*[ti] OR instruct*[ti] OR information[ti] OR program*[ti] OR programme*[ti] OR psychoeducation* OR psycho-education* OR "Psychotherapy/education"[mh] OR "self management" OR Self Care[mh]) Filters activated: English
CINAHL (EBSCO) PsycINFO (EBSCO)	(MH "Brain Injuries+" OR MH "Brain Concussion+" OR MH "Postconcussion Syndrome" OR "brain injury" OR "brain injuries" OR "brain injured" OR TBI OR "head injury" OR "head injuries" OR concussi* OR Postconcussi* OR Post-concussi*) AND (TI Educat* OR MH "Caregivers/ED" OR MH "Patient Education+" OR MH "Family+/ED" OR MH "Health Education+" OR MH "Consumer Health Information" OR TI teach* OR TI train* OR TI instruct* OR TI information OR TI program* OR TI programme* OR psychoeducation* OR psycho-education* OR MH "Psychoeducation" OR "self management" OR MH "Self Care+") English language (DE "Traumatic Brain Injury" OR DE "Brain Concussion" OR "brain injury" OR "brain injuries" OR "brain injured" OR TI TBI OR "head injury" OR "head injuries" OR concussi* OR Postconcussi* OR Post-concussi*) AND (TI Educat* OR DE "Client Education" OR "patient education" OR "family education" OR "caregiver education" OR DE "Health Education" OR DE "Drug Education" OR DE "Sex Education" OR TI "teach" OR TI "teaching" OR TI "training" OR TI "instruction" OR TI "instructions" OR TI "program" OR TI "programs" OR TI "programmes" OR TI "programme" OR psychoeducation* OR psycho-education* OR DE "Psychoeducation" OR "self management") English language
Cochrane Library (Wiley)	Line # Search terms #1 MeSH descriptor: [Brain Injuries] explode all trees #2 MeSH descriptor: [Brain Concussion] explode all trees #3 MeSH descriptor: [Post-Concussion Syndrome] explode all trees #4 (Traumatic brain injur* or brain injur* or TBI or head injur* or concussi* or Postconcussi* or Post-concussi*):ti,ab,kw #5 MeSH descriptor: [Caregivers] explode all trees and with qualifier(s): [Education - ED] #6 MeSH descriptor: [Patient Education as Topic] explode all trees #7 MeSH descriptor: [Health Education] explode all trees #8 MeSH descriptor: [Consumer Health Information] explode all trees #9 MeSH descriptor: [Psychotherapy] explode all trees and with qualifier(s): [Education - ED] #10 MeSH descriptor: [Self Care] explode all trees #11 (Educat* or teach* or train* or instruct* or information or program* or programme*):ti #12 (psychoeducation* or psycho-education* or "self management"):ti,ab,kw #13 (#1 or #2 or #3 or #4) #14 (#5 or #6 or #7 or #8 or #9 or #10 or #11 or #12) #15 #13 and #14
ABIEBR	This is not a database. It is an online "book" or literature review. We browsed it to locate the sections relevant to Traumatic brain injury and education.
Campbell Library PROSPERO PsycBITE	Searched each of these terms in Title field and then visually skimmed results to check for any relevance to the topic of educational interventions, training, or instruction: brain injury brain injuries head injury head injuries concussion consussions Postconcussion Post-concussion Postconcussive Post-concussive Searched each of these terms in Review Title field and then visually skimmed results to check for any relevance to the topic of educational interventions, training, or instruction: brain injury brain injuries head injury head injuries concussion

Database	Search Terms
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Intervention: Education/ Psychoeducation/Bibliotherapy
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Intervention: Family Support
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Keywords: "patient education"
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Keywords: "caregiver education"
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Keywords: "family education"
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Keywords: "patient information"
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Keywords: "patient training"
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Keywords: "caregiver training"
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Keywords: Psychoeducation
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Keywords: Psychoeducational
	Neurological Group: Traumatic brain injury (TBI)/Head injury AND Keywords: "self management"

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