A systematic review of peer mentoring interventions for people with traumatic brain injury

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Abstract

Objective: This systematic review sought evidence concerning the effectiveness of peer mentoring for people with traumatic brain injury.

Data sources: Fourteen electronic databases were searched, including PsycINFO, MEDLINE, CINAHL, EMBASE and the Cochrane Library, from inception to September 21 2016. Ten grey literature databases, PROSPERO, two trials registers, reference lists and author citations were also searched.

Review methods: Studies which employed a model of one-to-one peer mentoring between traumatic brain injury survivors were included. Two reviewers independently screened all titles and abstracts before screening full texts of shortlisted studies. A third reviewer resolved disagreements. Two reviewers independently extracted data and assessed studies for quality and risk of bias.

Results: The search returned 753 records, including one identified through hand searching. 495 records remained after removal of duplicates and 459 were excluded after screening. Full texts were assessed for the remaining 36
studies and six met the inclusion criteria. All were conducted in the United States between 1996 and 2012 and employed a variety of designs including two randomised controlled trials. 288 people with traumatic brain injury participated in the studies. No significant improvements in social activity level or social network size were found, but significant improvements were shown in areas including behavioural control, mood, coping and quality of life.

Conclusion: There is limited evidence for the effectiveness of peer mentoring after traumatic brain injury. The available evidence comes from small-scale studies, of variable quality, without detailed information on the content of sessions or the ‘active ingredient’ of the interventions.
Introduction

Traumatic brain injury is defined as an injury to the brain caused by a trauma to the head.\(^1\) Over 1 million people attend United Kingdom emergency departments for head injuries annually, with over 160,000 admitted to hospital.\(^2\)\(^3\) Worldwide, it is estimated that 10 million people sustain a traumatic brain injury every year.\(^4\)

Evidence suggests that around 70% of those with moderate to severe traumatic brain injury experience long-term physical, cognitive, emotional and behavioural problems,\(^5\)\(^6\) while significant numbers of people with minor head injuries also sustain long-term impairments.\(^7\)\(^8\)\(^9\) Brain injury transforms lives dramatically, reducing engagement in activities, impairing relationships and causing social isolation.\(^6\) Traditional rehabilitation services provide limited support to help people reduce social isolation and resume participation in meaningful activities. Therefore, it is important to investigate new and cost-effective intervention methods.

Peer mentoring is a potentially useful intervention which provides one-to-one support tailored to an individual’s needs. It is distinguished in this respect from
more traditional group peer support methods. The approach is defined as a process through which “an experienced individual encourages and assists a less experienced individual to develop his or her potential within a shared area of interest”. Peer mentoring has been used in a variety of contexts and has shown promise in the management of long-term health conditions such as spinal cord injury. The Brain Injury Association of the United States (BIAUSA) operates well-received peer mentoring programmes across the United States, but evidence of their effectiveness is anecdotal.

This systematic review sought evidence concerning the effectiveness of peer mentoring for people with traumatic brain injury. The primary goal was to inform the design and content of an intervention to be tested in a randomised controlled trial.

**Methods**

This review was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and a protocol was registered on the PROSPERO International Prospective Register of Systematic Reviews.
Studies of any design which employed a model of one-to-one peer mentoring between traumatic brain injury survivors were included. Studies were excluded if they employed group support models or exclusively used non-traumatic brain injury survivors in either mentor or mentee roles (including professionals, lay people or survivors of other forms of acquired brain injury). Conference abstracts (containing sufficient information) and grey literature were included.

Literature searches were developed across a range of databases using indexing terms (e.g., medical subject headings and Embase’s Emtree thesaurus) and text words relating to traumatic brain injury and peer mentoring. Social and leisure activity related terms were not searched in order to keep the search broad and avoid excluding any relevant studies. The search strategy was adapted to the requirements of each database. No wildcards or truncations were used.

The following 14 medical, health, social care and psychology databases were searched from time of inception to September 21 2016 (see appendix 1 for examples of the search strategy):
A search was conducted in the PROSPERO International Prospective Register of Systematic Reviews for ongoing reviews in the same topic area. Other research in progress was identified through Current Controlled Trials (www.controlled-trials.com) and Clinical Trials (www.clinicaltrials.gov) websites. Authors of any prospective studies were contacted. Grey literature searches were performed in Google Scholar, Google, Open Grey, the British Library Catalogue, US National Library of Congress, PsycExtra, Mednar, the TRIP Database, OAIster and PAIS International.
Reference lists of selected papers were hand searched. Citations for the authors of included studies were undertaken using the SCOPUS and Google Scholar citation search facilities.

Search results were exported directly into EndNote X7, with additional results added and duplicates removed. Two reviewers independently screened all titles and abstracts for relevance. Full texts were obtained for all potentially relevant articles. A third reviewer resolved any uncertainties regarding inclusion and authors were contacted when necessary for further information.

Data were extracted relating to aspects of study design and participant characteristics; details of the intervention (including details of social and leisure re-engagement); outcome measures; results and conclusions. Two reviewers extracted data independently using a bespoke data extraction form and assessed studies for quality and risk of bias using the Mixed Methods Appraisal Tool.21 Meta-analysis was inappropriate due to the scarcity of studies and heterogeneity of designs. Therefore, a descriptive synthesis of the data was undertaken.
Results

The database search returned 752 records with one further study identified through hand searching of reference lists. No studies were identified from the grey literature search or through citation searches of authors. 495 records remained after removal of duplicates and 459 were excluded after screening. Full texts were obtained where available for the remaining 36 records and 30 were excluded (see Appendix 2 for reasons) leaving a total of six studies to be included in the review. Figure 1 shows the flow diagram of the selection process.

Insert Figure 1 here

Appendices three, four and five provide details of studies included in the review and their findings.

Quality assessment of included studies

The studies were of low quality according to Mixed Methods Appraisal Tool criteria. Randomisation procedures and allocation concealment in the randomised controlled trials were poorly reported or not reported at all,
indicating risk of bias. Some of the papers combined description of an overarching peer mentoring programme with description of the research study itself, which often made quality assessment difficult. Both reviewers were forced to select ‘Can’t tell’ for many of the criteria on the Mixed Methods Appraisal Tool. This indicated low quality of reporting on many aspects of the studies and also meant that it was inappropriate to give each one a numerical score for the Mixed Methods Appraisal Tool.

**Study design and participant characteristics (see Appendix three)**

All six included studies were conducted in the United States between 1996 and 2012, two in San Jose, two in New York, one in Detroit and one in Houston. A variety of study designs were employed including one single centre pilot randomised controlled trial, one single centre randomised controlled trial, one quasi-experimental study, one before-and-after design, one concurrent mixed methods design and one service description. All interventions took place in a community setting.

Information provided on participant numbers and demographics varied widely among the studies. Only one provided a detailed demographic breakdown of
both mentors and mentees, including by injury severity. A total of 288 people with traumatic brain injury participated across the studies (excluding the Moreci paper which wasn’t a research project and didn’t report numbers). Some studies also looked at mentoring for significant others but this paper focuses on traumatic brain injury survivors.

Mentor eligibility characteristics included social competency, absence of psychiatric issues or criminal history, willingness, motivation, commitment, empathy, insight and ability to listen and talk openly. There were differences between all the studies in the criteria employed. One project hired mentors as contingent employees. This was cited as a method of maximising mentor engagement and improving on the studies of Struchen et al and Hibbard et al.

Only one study reported detailed criteria for mentee eligibility. The others reported few criteria other than age and having sustained a traumatic brain injury.
Details of intervention (see Appendix four)

One study aimed specifically at improving social integration and social participation. Other clearly defined aims were: to improve emotional wellbeing, post-injury quality of life and community integration; reducing isolation by providing social support and validation of personal experience; and improving individuals’ abilities to access and utilise community services. Hibbard et al (2002) were the only authors to describe an underpinning theory, or conceptual framework for their study. This was participatory action research, which seeks to engage community members in the research process and involve them as active participants. Hanks et al also briefly mention participatory action research but only in relation to the development of the questionnaire for the study.

Limited information was provided on the content of mentoring sessions other than topics intended for discussion, which included emotional wellbeing, post-injury quality of life and community integration. Support staff employed included psychologists (acting as supervisors, trainers and emergency contacts), programme co-ordinators and a vocational counsellor.
The timing of the interventions post-injury varied. One study provided the intervention within two days of discharge from rehabilitation and another while still in the rehabilitation unit. Mentees in one study were reported to be a mean of 503 days post-injury (although this does not specify those with brain injury), and another a median of 1.6 years post-injury. The ways these figures are reported are inconsistent and it isn’t possible to provide a range of time post-injury for participants in all studies. This also applies to the mentors in the studies. One study required mentors to be a minimum of two years post-injury, while one reported mentors to be a median of 6.2 years post-injury. Others provided few details.

The criteria by which pairs were matched varied across the studies and included age, gender, role (traumatic brain injury survivor/carer), interests, background, injury effects and geographic area. Two studies relied on the judgement of the study team to provide a mentor best suited for the needs of the mentee.

Frequency, duration and intensity of the interventions varied considerably within and between studies. Some researchers established guidelines for minimum numbers of contacts but these were rarely met. Only one paper provided
details of the time duration of contacts.\textsuperscript{26} Duration of partnerships varied from three months\textsuperscript{27} to indefinite\textsuperscript{24} (excluding the Moreci service description paper), while reported number of contacts ranged from 1 – 108.\textsuperscript{24, 26, 27} The nature of the contacts was generally left up to the participants and could be in-person, telephone or email (Struchen et al allowed a variety of contact methods but only detailed numbers of in-person contacts). The actual content of the sessions was not recorded and isn’t reported in any of the papers.

Detailed information on mentor training sessions was provided in several papers.\textsuperscript{23, 24, 26, 27} Common elements of training included communication skills, listening skills, advocacy, knowledge of traumatic brain injury, and knowledge of community resources. Only one paper mentioned training mentors to handle crisis situations.\textsuperscript{27} Regular refresher sessions were described as important.

There was considerable overlap between the programmes in the logistical challenges they encountered. These can be summarised as follows:

- Problems scheduling times and locations for meetings
- Budgeting for transport
- Identifying suitable mentors
- Providing sufficient staff support time
• Making allowances for the mentors’ cognitive difficulties
• Partners living too far apart
• Too many matching criteria
• Loss of participants’ interest due to delay between enrolment and matching
• Lack of accessible meeting locations
• Lack of potential participants’ interest in the research aspect of the programmes
• Difficulty recruiting participants from diverse socio-demographic/ethnic groups and people with minor brain injury
• Inability to identify the mechanisms influencing study outcomes

Only one study looked specifically at improving social integration and participation.27 Other studies included aspects of community integration, social support and reducing isolation as among the aims of their projects and included measures of these factors.22, 24, 26
Outcome measures, follow-up periods, results and conclusions (see Appendix five)

The Craig Handicap Assessment and Reporting Technique Short Form (CHART-SF)\(^\text{30}\) and the Diener Satisfaction with Life Scale \(^\text{31}\) were administered in two studies.\(^\text{22, 27}\) All papers (with the exception of Moreci) included different measures of mood and behaviour, such as depression, anxiety, alcohol use, coping and empowerment, and two included open-ended satisfaction questionnaires.\(^\text{26, 27}\) Qualitative interviews of significant others were employed in one study.\(^\text{24}\)

There were considerable differences in the data collection follow-up periods used in the studies. One of the randomised controlled trials collected data once, 12 months after completion of the intervention, and didn’t record baseline measures.\(^\text{26}\) One study was a retrospective design so measures were only administered at programme completion.\(^\text{24}\) One study collected data at baseline and programme completion;\(^\text{25}\) one at baseline and three-months;\(^\text{27}\) and one at a minimum of four time points.\(^\text{22}\)
No significant improvements in social activity level or social network size were found\textsuperscript{27} and there were no significant improvements in Craig Handicap Assessment and Reporting Technique social integration scores.\textsuperscript{22, 27} Minimal impacts were observed on enhancing social support from families, friends and the community.\textsuperscript{24} Significant improvements were found in community integration and independence.\textsuperscript{22} There was a trend towards increased satisfaction with social life in the past month\textsuperscript{27} and 30 of 57 traumatic brain injury participants successfully achieved goals of returning to employment or education.\textsuperscript{22} Significant improvements of note were shown in measures of behavioural control; chaos in the living environment; alcohol use; emotion-focused coping; physical quality of life;\textsuperscript{26} perceived social support;\textsuperscript{27} depression; empowerment; coping; life satisfaction and communication with healthcare professionals.\textsuperscript{25} Significant increases in depression were also observed in one study.\textsuperscript{27} High levels of satisfaction among both mentors and mentees were reported across all six studies and positive impacts observed on increasing knowledge of traumatic brain injury; overall quality of life; improving general outlook; and ability to cope with depression.\textsuperscript{24} Outcomes were not provided according to severity of injury. The results should be interpreted with caution due to the limitations of the studies.
Each of the papers concluded that one-to-one peer mentoring showed promise as an intervention for traumatic brain injury survivors, gained high satisfaction ratings, and that further research was needed. It was recommended that future research should identify the most useful components of the intervention and that small sample sizes and limited ‘dosage’ of interactions were limitations that should be addressed in a future trial.\textsuperscript{26, 27}

**Discussion**

There is a lack of high-quality published evidence for the effectiveness of peer mentoring after traumatic brain injury. The evidence available comes from small-scale studies of limited quality conducted in the United States. The studies covered fairly brief intervention periods and provided limited information on long-term success or sustainability. Despite concerns about the quality of the studies and their generalisability, they produced some promising results and provided useful information regarding the conduct of peer mentoring research. Overall, the potential for peer mentoring to impact on social and leisure participation (among other outcomes), and the optimum design of an intervention, remain unclear. Further research is required to determine the efficacy of peer mentoring interventions for traumatic brain injury survivors.
The heterogeneity of the studies, including designs, time scales and follow-up periods, makes it difficult to compare them and draw clear conclusions. Only two randomised controlled trials have been conducted and these were both of low quality in terms of randomisation procedure.\textsuperscript{26, 27} One was a pilot study with just 12 mentored participants,\textsuperscript{27} while the larger trial compared mentored and control groups without recording baseline measures.\textsuperscript{26} Hibbard’s 2002 study also did not take measures at baseline and relied on subjective self-reporting to assess the impact of the intervention.\textsuperscript{24} The mixture of neurological disabilities studied by Kolakowsky-Hayner et al mean that many of the results cannot be interpreted as applying specifically to people with traumatic brain injury.\textsuperscript{22} Also, one of the included studies was a conference abstract with minimal information on methodology\textsuperscript{25} and another was a service description with no assessment of outcomes.\textsuperscript{23}

Despite the limitations of the studies, the range of significant improvements on mood and lifestyle measures provides some evidence for their effectiveness. The results suggest that a peer mentor could help traumatic brain injury survivors to modify problem behaviour and employ healthier coping strategies. The impact of peer mentoring on social and leisure participation is uncertain,
with only one study looking specifically at social peer mentoring and reporting mixed results. However, the significant increase in perceived social support, trend towards improved satisfaction with social life, gains in community integration and independence, and subjective reports of enhanced social support are all encouraging. Significantly more evidence would be required before firm conclusions can be drawn regarding any outcomes.

Unfortunately, there was little to be learned from the studies in terms of the content of mentoring sessions. It is not known whether discussions in sessions kept to the intended topics and or what activities took place. There was also considerable variation in the nature of the contacts (with most studies allowing in-person, telephone or email correspondence), the frequency of contacts and duration of partnerships. Consistent implementation of these variables is important in order to understand the factors, or ‘active ingredients’, which influenced outcomes.

Only one of the articles reports any level of detail regarding an underpinning theoretical framework to the study and this refers to participatory action research. Other theories which could be used to inform the development of peer mentoring for disability groups have been suggested by Hayes and
Balcazar, such as the ecological principles of community psychology and the social-ecological model of disability.\textsuperscript{32} Similarly to participatory action research, these ideas centre on thinking about disabled people as useful resources in their community, and on the importance of adapting a person’s environment in order to reduce the impact of their disability. Other conceptual frameworks which could usefully inform mentoring programmes include socio-cognitive approaches, such as Bandura’s self-efficacy theory,\textsuperscript{33} and theories of motivation and leadership, such as personal construct theory\textsuperscript{34} and transformational leadership theory\textsuperscript{35} (utilised by an ongoing, unpublished study in Wales of ‘peer coaching’ after stroke).

Despite the studies’ methodological problems there is much to be learned from the mentor training programmes, assessments of logistical challenges and participant evaluations.\textsuperscript{22-24, 26, 27} It is important that future studies train mentors thoroughly and build on the training programmes described in the papers and published online.\textsuperscript{24, 26, 27} The logistical challenges described will also need to be considered and can potentially be avoided by careful planning of the intervention model. Finally, the positive feedback from the majority of participants indicated that the interventions were enjoyable and subjectively beneficial.
It should be noted that one further study has recently been conducted in New Zealand from which a conference poster has been published reporting positive experiences of participants.\textsuperscript{36} This was identified in a recently updated literature search and the full data from the study has not yet been published.

The strength of this systematic review was the robust methodology. The search strategy was carefully designed and a large number of relevant databases were searched, while two reviewers independently conducted all screening, data extraction and quality assessment. Grey literature searches, hand-searching of reference lists, author citation searches and correspondence with authors also strengthened the study.

The specificity of the research question to traumatic brain injury could be considered a limitation of the review. Two published abstracts referring to an acquired brain injury (ABI) peer mentoring study in Canada were excluded as they didn’t contain information regarding traumatic brain injury survivors.\textsuperscript{37, 38} A case study which involved a traumatic brain injury survivor mentoring an encephalitis survivor was also excluded.\textsuperscript{39} As similar issues apply to people with all forms of brain injury it may be appropriate to widen the scope of a future review to include all ABI.
Clinical messages

- Definitive evidence is lacking for the effectiveness of peer mentoring after traumatic brain injury
- The few studies conducted showed promising results
- The majority of studies have not described a theoretical framework
- The identified studies do not describe the content of sessions or identify the ‘active ingredient’ of peer mentoring

Acknowledgements

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Competing interests and source of funding

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Contributors

RM developed the search strategy, performed all searches, removed duplicate records, screened all titles and abstracts and extracted data from the included full papers. RM was lead reviewer and lead author of this systematic review paper.

JFS is an experienced systematic reviewer and acted as mentor to RM throughout the design phase of the systematic review protocol. JFS was second reviewer, assisting RM with the screening of unduplicated titles and abstracts, and the data extraction and quality assessment of included studies. JFS co-authored this paper.
KR devised the research question that this systematic review sought to address. KR acted as third reviewer in cases of uncertainty over the inclusion or exclusion of studies. KR co-authored this paper and had overall responsibility for the successful completion of the systematic review.

References


Appendix one – search strategy for selected databases

Database: Ovid MEDLINE 1946 to September week 1 2016 (adapted for other databases hosted on Ovid)

1 exp Brain injuries/ OR exp craniocerebral trauma/ OR exp intracranial hemorrhage/ OR exp Brain Concussion/ OR brain injury.mp. OR brain injuries.mp. OR head injury.mp. OR head injuries.mp. OR traumatic brain injury.mp. OR traumatic brain injuries.mp. OR head trauma.mp. OR craniocerebral trauma.mp. OR brain trauma.mp. OR acquired brain injury.mp. OR acquired brain injuries.mp. OR diffuse axonal injury.mp. OR diffuse axonal injuries.mp. OR concussion.mp. OR brain damage.mp. OR subarachnoid haemorrhage.mp. OR subarachnoid hemorrhage.mp.

2 peer support.mp. or mentor.mp. or mentoring.mp. or mentors.mp. or mentorship.mp. or peer coach.mp. or peer coaching.mp. or peer coaches.mp. or peer counselling.mp. or peer counsellor.mp. or peer counsellors.mp. or peer counseling.mp. or peer counselor.mp. or peer counselors.mp. or peer partner.mp. or peer partners.mp. or peer partnering.mp. or peer tutor.mp. or peer tutors.mp. or peer tutoring.mp. or peer trainer.mp. or peer training.mp. or peer trainers.mp. or peer education.mp. or peer educator.mp. or peer educators.mp. or peer teacher.mp. or peer teachers.mp. or peer teaching.mp.

3 1 AND 2


1. (MH “head injuries”)
2. (MH “brain injuries”)
3. (MH “brain concussion”)
4. (MH “intracranial hemorrhage”)
5. (MH “brain damage, chronic”)
6. (MH “cerebral hemorrhage”)
7. TX brain injury
8. TX brain injuries
9. TX head injury
10. TX head injuries
11. TX head trauma
12. TX brain trauma
13. TX diffuse axonal injury
14. TX brain damage
15. TX concussion
16. TX subarachnoid haemorrhage
17. TX subarachnoid hemorrhage
18. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17
19. TI Peer support OR mentor OR mentoring OR mentors OR mentorship OR peer coach OR peer coaching OR peer coaches OR peer counselling OR peer counsellor or peer counsellors OR peer counseling OR peer counselor or peer counselors or peer partner or peer partners or peer partnering or peer tutor or peer tutors OR peer tutoring OR peer trainer OR peer training OR peer trainers OR peer education OR peer educator OR peer educators OR peer teacher OR peer teachers OR peer teaching
20. AB Peer support OR mentor OR mentoring OR mentors OR mentorship OR peer coach OR peer coaching OR peer coaches OR peer counselling OR peer counsellor or peer counsellors OR peer counseling OR peer counselor or peer counselors or peer partner or peer partners or peer partnering or peer tutor or peer tutors OR peer tutoring OR peer trainer OR peer training OR peer trainers OR peer education OR peer educator OR peer educators OR peer teacher OR peer teachers OR peer teaching
21. SU Peer support OR mentor OR mentoring OR mentors OR mentorship OR peer coach OR peer coaching OR peer coaches OR peer counselling OR peer counsellor or peer counsellors OR peer counseling OR peer counselor or peer counselors or peer partner or peer partners or peer partnering or peer tutor or peer tutors OR peer tutoring OR peer trainer OR peer training OR peer trainers OR peer education OR peer educator OR peer educators OR peer teacher OR peer teachers OR peer teaching
22. 19 OR 20 OR 21
23. 18 AND 22
# Appendix two - Excluded papers and reasons for exclusion

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<tr>
<th>Number</th>
<th>Study ID</th>
<th>Reason for exclusion</th>
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<tr>
<td>5</td>
<td>Boschen K. Evaluation of an Ontario ABI peer support mentoring program. <em>Archives of Physical Medicine and Rehabilitation</em> 2012; 93 (10): E28-E29.</td>
<td>Conference abstract with insufficient information to identify traumatic brain injury participants. Contact with author gleaned information relevant to study but results unpublished and unsuitable for assessment within this systematic review.</td>
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<tr>
<td>9</td>
<td>Fraas M, Bellerose, A. Mentoring programme for adolescent survivors of only the mentor had traumatic brain injury, not the mentored participant.</td>
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| 12 | Haarbauer-Krupa J. Readiness for independence: Facilitation of the transition to adulthood for teens with ABI. *Journal of Head Trauma Rehabilitation* 2011; 26 (5): 433. | Conference abstract with limited information. Refers to 'peer coaches' and author was contacted for further information. The coaches were college students although some self-identified as having traumatic brain injury. No traumatic brain injury specific data has been collected. |
| 17 | MacEachen E, Kosny A, Ferrier S. Unexpected barriers in return to work: Lessons learned from injured worker. | This was for any type of injury preventing return to the place of
<table>
<thead>
<tr>
<th>Reference</th>
<th>Description</th>
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<tr>
<td>19 Rowden-Racette K. 2009</td>
<td>Mentoring program relieves staffing shortages. <em>ASHA Leader</em> 2009; 14 (11): 26. This is a staff mentoring program not a brain injury peer mentoring program.</td>
</tr>
<tr>
<td>25 Tennille T, Leisa E.</td>
<td>Does social isolation improve for Vietnamese people with brain injury (BI) when they participate in client led culturally sensitive peer groups. <em>Brain Impairment</em> 2013; 14 (1): 209. Appears to be a group intervention rather than peer mentoring and no further information could be obtained from the author.</td>
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<td>Reference</td>
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# Appendix three - Study design and participant characteristics of studies identified in systematic review

Information in this table is adapted from the text of the papers, along with comments on missing information where relevant. Extended direct quotes from the papers are italicised and in quotation marks.

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<tr>
<td>Context/setting</td>
<td>San Jose, USA. Community.</td>
<td>San Jose, USA. Rehabilitation unit for visits and community for phone calls.</td>
<td>New York, USA. Community.</td>
<td>New York, USA. Community.</td>
<td>Detroit, USA. Community.</td>
<td>Houston, USA. Community.</td>
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<tr>
<td>Participant recruitment</td>
<td>No details.</td>
<td>Social services referred patients on rehab unit and their families. No details of mentor recruitment.</td>
<td>Programme ppts recruited through website, outreach coordinators, independent living centres, rehabilitation hospitals, support groups and conferences. The first 52 partners to enrol in the TBI-Mentoring Partnership Programme who had completed their partnerships were invited to participate in the research project.</td>
<td>No details. TBI survivors (and their significant others) who were enrolled in the South Eastern Michigan TBI System were approached individually. Mentors were hired as contingent employees in order to maximise engagement. No other details of how mentors were recruited or where from.</td>
<td>Recruited through outpatient clinics at 2 rehabilitation hospitals, via in-person, written and online methods. Potential participants were informed that they may be either a mentor or peer partner.</td>
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<tr>
<td>(mentors and mentees)</td>
<td>Mentees: Aged between 16 and 26. 89 mentees successfully matched and participated through to completion of the programme of which 57</td>
<td>Mentees: Not stated.</td>
<td>Mentees: 20; 11 TBI and 9 family members. Male = 6, Female = 14; African-American (4), White, (14), other (2). Age: &lt;19 (1); 19-30 (1); 31-45 (12) &gt;46 (6).</td>
<td>Mentees: Intervention group: 64 individuals with TBI and 30 family members: Control group: 30 individuals with TBI and 10 family members.</td>
<td>Mentees: People with TBI (n=96) and significant others/caregivers (n=62). 47 TBI mentees, 49 TBI control group members,</td>
<td>Mentees: N = 30; mentoring condition – 12; control condition – 18. Age, mean [min-max] = 31.7 [21–68]. Gender – Male = 24. White – 14; Black – 7;</td>
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<td>and demographics</td>
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had TBI. 12 were still engaged in mentoring at conclusion of programme and were excluded from analysis. 77 were included in the analysis. Demographic details of participants are provided but not for TBI participants. Mentors: N = 121 (29% with TBI).

Mentors: Provided for programme as a whole but not for mentors of study participants. To determine whether the sample of partners who participated was representative of the larger pool of partners, chi square statistics and t tests were computed on select demographic variables comparing study participants with partners who declined the interview. No significant differences between the two subgroups were found.


Mentor eligibility

| Mentor eligibility | Minimum 2 years post injury and with a high level of acceptance and successful integration into community (e.g., working or post-secondary education). | Experience with TBI, positive references and personal attributes such as genuineness, ability to listen, appropriate empathy and a positive regard for people. | Willingness to volunteer necessary time; successful personal adjustment to TBI; insight into limitations and strengths; absence of psychiatric problems; ability to listen and empathize; ability to inhibit personal responses when necessary. | No details. | Evaluated on social competency, willingness to talk openly about disability and life experiences, motivation, and commitment to participation. | Medically documented TBI and community-dwelling; >18; not in a rehab program; criminal background check; references; minimum Social Integration subscale score of 100 on CHART-SF. |

| Hispanic – 8; Other – 1 |
| Injury severity: Mild – 6; Severe – 22 (2 missing). |
| Mentee eligibility | Individuals with TBI, SCI and other neurological conditions between the ages of 16 and 26. | No details. | Excluded if: risk of suicidal or violent behaviour; had psychiatric/substance abuse problems; Inability to articulate reasons for wanting peer support; no personal interest in receiving peer support; excessive negativity, anger/volatility; severe cognitive impairments; no awareness of brain injury effects; no desire to change life situation. | Individuals with TBI and their family members. | TBI survivors: >16. Must be clear of post-traumatic amnesia. Significant others: >18, knew the care recipient prior to brain injury and considered to be active carer. | Medically documented TBI and community dwelling. >18 years of age. No longer participating in rehab programme. |
Appendix four: Details of the intervention in studies identified in systematic review

Information in this table is adapted from the text of the papers, along with comments on missing information where relevant. Extended direct quotes from the papers are italicised and in quotation marks.

|--------------------------------------------|-------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Kolakowsky-Hayner et al 2012 (reference no. 22) | Improve the ability of an individual with disabilities to access and maximally utilize the services and programs that are available in the community. | "Understanding the difficulties that are encountered, as well as the breakthroughs possible, we support one another."                                                                                                            | "To reduce isolation by providing social support and validation of personal experiences by "someone who has been there before."
"With the aim of increasing the validity of research findings and empowering consumers, a paradigm of participatory action research (PAR) was incorporated into all aspects of the TBI-MPP. Strengths of PAR include the innovative adaptation of methods for use in a variety of different contexts, exploration of the knowledge and perceptions of community members, involving members of the community as active participants, and facilitating the equitable distribution of power in the process of research so that community members are regarded by themselves and others."
| No details.                                | To improve: (1) emotional wellbeing; (2) post-TBI quality of life; and (3) community integration. | "Using a participatory-action research approach, persons with TBI and their significant others who were not directly involved with this project helped to develop a satisfaction questionnaire to evaluate this program."                                                                 | Improving social integration and participation in adults with TBI.                                                                                              |                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                    |
**Content and components of intervention delivery**

| **Content and components of intervention delivery** | **Program staff consisted of two physicians, a Program Coordinator, a Program Assistant, a Vocational Counsellor, and a Rehabilitation Psychologist. The Mentoring Program Coordinator monitored the progress of the relationships on a semi-monthly basis and served as a liaison to a Vocational Rehabilitation Counsellor for purposes of vocational planning. The Rehabilitation Psychologist assisted with psychosocial concerns that arose with the mentee-mentor relationship.” | The Peer Supporter provides a listening ear and a sensitive awareness of the many issues concerning TBI. Individual structured peer support visit in the rehabilitation unit. Peer supporters visit the rehabilitation centre in teams of two, three nights each week for two hours. Peer Supporters also make phone calls to offer support to individuals and their families who have left the rehabilitation unit. | “TBI "veterans" were matched with individuals with TBI or family members to provide emotional support, knowledge about TBI and resources, and advocacy skills. The programme was designed to address both the acute and long-term adjustment needs of individuals with TBI and their family members.” | No details. | Discussions in mentoring sessions were focused on: emotional well-being; post-TBI quality of life; and community integration. Mentors provided social and emotional support, helping the mentee gain access to community resources, and discussion of any topics related to TBI or caregiving that the mentee wanted to discuss. “Mentors were hired as contingent employees and involved in weekly in-person supervision from a psychologist, a nurse, and community outreach coordinator. These supervisors were available for 24-hour emergency assistance.” | Goal of outings to foster increased social networking for the PP through introductions to people, activities and community resources. On-call therapist spoke to SPMs by phone at least once per week and often assisted with problem-solving. Was always available by pager in the event of an emergency and provided training booster sessions. |

**Timing (time post-injury intervention was delivered)**

| **Timing (time post-injury intervention was delivered)** | No specific details. Mentees average of 503 days post-injury. | Initial contact in rehabilitation unit. | Various stages of recovery. Not specifically stated. | No details. | Participants were contacted by their peer mentors prior to discharge or within 2 days of discharge from inpatient rehabilitation. | Various stages. Mentees a median of 1.6 years post injury. |

**Matching criteria**

| **Matching criteria** | Each mentee was matched with a community-based mentor who may or may not have a disability although efforts were | Not applicable. Peer supporters visit several patients in each visit. Long term relationships encouraged but no | Based on needs of participant. Criteria included; similar demographic background; similar marital or family status; | No details. | Matched by the study coordinator by sex and role (e.g., person with TBI vs significant other), and each mentee only had 1 mentor. | “Social mentors were matched to their PPs on the basis of group consensus of the research team using the following criteria:” |
| Frequency, duration, intensity and fidelity of implementation. | Minimum of 3 contacts per month through in-person, telephone, or electronic mail methods. Not time limited. Formal exit from the program was scheduled to occur 4 months after the individual with disability attempted to return to post-secondary education or employment. Some pairings continued their relationship actually outside the auspices of the formal mentoring program. | Visits occur three nights each week from 18.00 h to 20.00 h. Two hours is enough time to visit with at least four patients and their families. The relationship between peers can grow into a long term connection and reduce the chance for isolation and depression. | The duration of the partnership and its intensity are mutual decisions of the mentor and his or her partner. On average, mentors and partners participating in the study had 13 contacts with mentors, with wide variation in the number of contacts made per partnership (SD = 12.77). One partnership was excluded from the analysis as an outlier because they had more than 108 documented contacts. | Mentors arranged for a meeting within 2 weeks of initial contact and were requested to meet and/or talk via telephone at least weekly for the first month, biweekly for the next 2 to 3 months, and then monthly for the remainder of the first year. Contact more frequent than these minimum guidelines was encouraged as appropriate. Formal mentoring lasted for 1 year. Although mentees were encouraged to continue the relationship with their mentors during the second year if desired. Contacts were mostly 5 to 15 minutes (36%), followed by contacts lasting 16 to 30 minutes (30%), 31 to 60 minutes (19%), and 15% greater than an hour. | No details. | Active peer mentoring occurred over a 3-month period. Mentor (SPM) responsible for making initial contact within 1 week after receiving their partner’s (PP) details. SPMs were asked to set up initial outing. Additional contacts could be initiated by either party. SPM responsible for ensuring that each respective PP participated in a minimum of 2 outings per month. Only half of the SPM-PP matches met for the minimum number of outings (6), and only 2 matches exceeded the minimum outing requirements. |
**Mentor training**

<table>
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<tr>
<th>Description</th>
<th>Details</th>
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<tr>
<td>Mentors underwent a training curriculum and refresher sessions throughout the program under the facilitation of a Rehabilitation Psychologist and the Program Coordinator. Training was based on the structure of the traumatic brain injury (TBI) and spinal cord injury (SCI) Peer Support Program volunteer training at our facility (no further details on this provided).</td>
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<tr>
<td>&quot;Hospital neuropsychologist and experts in the area of grief process, active listening, communication, hospital procedures, and basic brain injury education train the peer supporters once per year. Training is an ongoing process. During bi-monthly training meetings, the volunteer Peer Supporters are given an opportunity to discuss challenges to providing support, enhancing communication skills, basic procedures of the job, and important issues regarding grief, TBI and resources. There is also a social component to the bi-monthly meetings to provide an opportunity for the volunteers to get to know each other better. A cohesive group is important and allows the peer supporters to receive emotional support from each other.&quot;</td>
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<td>&quot;A mentor training manual was developed. A series of 8 full-day mentor training workshops was held over the course of the first 2 years of the project. At these workshops, mentors received training focused on enhancing their communication, listening, and advocacy skills and increasing their knowledge of TBI and community resources. Because most communication between partners and mentors is by telephone, training emphasized communication skills using this modality.&quot;</td>
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<tr>
<td>No details.</td>
<td>No details.</td>
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<tr>
<td>Curriculum and training manuals included: (1) introduction to the peer-mentoring project; (2) effects of TBI, and disability awareness; (3) practical skills beneficial in any helping relationship; (4) practice of new skills with 2 case studies and feedback from supervisors and other trainees; and (5) resources from the State of Michigan TBI Resource Guide developed by the Health Related Services Administration-funded State of Michigan TBI grantee program. Mentors participated in 20 hours of training, and all mentors were trained at the same time. Interactive training consisted of (1) modelling interviewing skills with a supervisor and fellow trainees; (2) telephone role playing; (3) discussion of what is and what is not mentoring; (4) communication skills and active listening; and (5) review of documentation responsibilities for the study.</td>
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</table>

Minimum number of contacts should be 18. Actual number of contacts averaged 5.4 so on average did not meet minimum guidelines.
| Evaluation | Both mentor and mentee completed a questionnaire which documented satisfaction with the mentor relationship. | A satisfaction survey is given to participants. | Both qualitative and quantitative interviews examined the partners' satisfaction with their partnerships and their mentors. | Brief interview developed and administered to assess programme impact. | Mentees given a Peer Mentoring questionnaire based on tool developed by Hibbard et al. | All participants (SPMs and PPs) completed a satisfaction survey regarding their perceptions of the peer-mentoring and evaluation experience. |
| Logistical challenges and study limitations | Large geographic area meant locations of participants made it difficult for them to meet. Too many matching criteria limited the ability to make quick matches. The time between participant enrolment and matching was very lengthy, impacting mentees' interest to remain in the program. Lack of accessible locations to meet, difficulty with varying schedules, etc, made meeting up difficult. Participants would have liked the program to include more structured programs and activities. | Not applicable. | "Most partners sought out the TBI-MPP primarily because they were interested in receiving peer support and not because they were motivated to participate in a research project. As a result, partner compliance with the "traditional" research aspects of the program was poor." | No details. | High rate of indigent and poor patients, whose access to health care and related resources prior to the injury was likely lower than that experienced by the general population of persons with TBI. These factors may heighten or otherwise differentiate the response to resources provided. Relatively restricted representation of persons with moderate-to-severe TBI and their significant others. The exact mechanism of change was not fully investigated in this study, and it would be beneficial for future studies to deconstruct the intervention to determine such mechanisms. | Primarily logistic. Issues such as problems with scheduling times/locations and transportation/ budget limitations were difficult barriers to overcome. Identifying mentor candidates that were suitable matches was a particular challenge, with distance between available SPMs and PPs being the primary difficulty. Another issue was the need for substantial staff support time for assisting some of the mentors. Some mentors had cognitive limitations as a result of their own injuries that made certain aspects of identifying and facilitating social events for their PPs taxing. Cognitive limitations present for many of the PP participants also presented obstacles to planning and follow |
| Details of social and leisure re-engagement | Details provided of number of times mentors logged their mentees interest in a specific topic. Relaxation (379 times); Family/friends (358); Relationship issues (354). Significant community integration and independence improvements were noted for program participants (CHART Mobility and Cognitive Independence, M2PI, DRS, and SRS). | No information. Author states that more research is needed on effect of peer relations on social isolation and depression in people with TBI. | Impact on social support from friends was reported by a small group of participants (a “major impact” by 18% of individuals and 11% of family members, with “some impact” for an additional 22% of family members). Minimal impact was noted on enhancing social support from the community at large (11% “major impact” by family members and 9% “some impact” for individuals). | No details. | The majority of mentees were satisfied with their experience, and felt that it helped with social support. | Goal of outings to foster increased social networking for the PP through introductions to people, activities and community resources. Social integration was not shown to significantly improve, although changes in social integration scores were in the predicted direction for mentored ppts. Small positive changes were noted for mentored PPs in the areas of social network size, participation in highly valued activities, and activities involving persons other than family; however, these changes were not statistically significant and were also noted for those in the WL. |
Appendix five: Outcome measures, follow-up periods, results and conclusions of studies identified in systematic review

Information in this table is adapted from the text of the papers, along with comments on missing information where relevant. Extended direct quotes from the papers are italicised and in quotation marks.

<table>
<thead>
<tr>
<th>Study</th>
<th>Outcome measures</th>
<th>Data collection method</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Kolakowsky-Hayner et al 2012 (reference no. 22)</td>
<td>Disability Rating Scale (DRS); the Participation Index of the Mayo-Portland Adaptability Inventory – Version 4 (M2PI); the Supervision Rating Scale (SRS); the Craig Handicap Assessment and Reporting Technique – Short Form (CHART-SF), and the Diener Satisfaction with Life Scale (SWLS). Programme satisfaction questionnaire.</td>
<td>Retrospective structured interview assessing self-reported impacts of peer support on empowerment, quality of life, mood, skills and knowledge, and social supports; an in-depth qualitative interview with a subgroup of family members focused on the specific benefits/limitations of the program. Interview questions adapted from four existing measures: the Questionnaire on Resources and Stress–Short Form (QRS-SF); the Frequency of Family Coping Behaviours (FCB), the Social Support Questionnaire Short Form (SSQ-SR), and the Empowerment Scale. Validation of the</td>
<td></td>
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<tr>
<td>Moreci 1996 (reference no. 23)</td>
<td>Not applicable.</td>
<td></td>
<td>Peer Mentoring Questionnaire; Brief Symptom Inventory-18; Family Assessment Device; Coping Inventory for Stressful Situations; Short Michigan Alcohol Screening Test; Medical Outcomes Study 12-Item Short-Form Health Survey; and Community Integration Measure.</td>
</tr>
<tr>
<td>Hibbard et al 2002 (reference no. 24)</td>
<td>Beck Depression Inventory-II, Beck Anxiety Inventory, coping and empowerment measures, brief interview developed to assess program impact.</td>
<td></td>
<td>CHART-SF (Physical Independence, Cognitive Independence, Mobility, Occupation, and Social Integration subscales); Social Activity Interview (SAI); Center for Epidemiological Studies Depression Scale; UCLA Loneliness Scale – Version 3; 6-item Interpersonal Support Evaluation List; Satisfaction with Life Scale; Weekly Social Activity Survey; Peer Partner Satisfaction Survey; Mentor Satisfaction Survey.</td>
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<tr>
<td>Hibbard and Cantor 2005 (reference no. 25)</td>
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<td>Hanks et al 2012 (reference no. 26)</td>
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<td>Struchen et al 2011 (reference no. 27)</td>
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Follow up periods

| Minimum of four assessments: At time of enrolment; three months; every three months until attempted entry to employment or post-secondary education; four months after entry to employment or education. | Not applicable. | Post study completion. | Baseline and after programme completion (no further details). | 12 months after completion of mentoring. Comparison was between the groups. | One month baseline and three-month peer mentoring period. Equivalent four-month period for wait list participants. |

Results

- “Of those with education goals, 23/53 achieved educational goals and 7/53 achieved employment goals. Of those with vocational goals, 5/12 achieved vocational goals and 1/12 achieved educational goals. Of those with both goals, 5/12 achieved educational goals and 1/12 achieved vocational goals. Significant community integration and independence improvements were noted for program participants (CHART Mobility and Cognitive Independence, M2PI, DRS, and SRS).”

- “Participants in the peer support program reported positive impacts of peer support on increasing their knowledge of TBI, enhancing their overall quality of life, improving their general outlook, and enhancing their ability to cope with depression post TBI. The peer support program was reported to have had a minimal impact on enhancing social support from families, friends, and the community, with varying impacts noted on levels of happiness, coping with anger and anxiety, communication with professionals, and control over one’s life. Qualitative analysis”

- “After program participation, the partner group showed statistically significant improvements in depression ($P < 0.05$), empowerment ($P < 0.05$), life satisfaction ($P < 0.05$), coping ($P < 0.05$), and communication with health care professionals ($P < 0.01$). The controls exhibited no significant changes. There was a significant group by time interaction for depression ($P = 0.042$), empowerment ($P = 0.007$), life satisfaction ($P = 0.032$), coping ($P = 0.018$), and communication with health care professionals ($P = 0.001$).”

- “Eighty-eight percent of individuals who were involved in the mentoring program reported positive experiences. t tests revealed that among persons with TBI, individuals who received mentoring had significantly better behavioural control and less chaos in the living environment ($P = .04$), lower alcohol use ($P = .01$), less emotion-focused ($P = .04$) and avoidance coping ($P = .03$), and good physical quality of life ($P = .04$) compared with those who did not receive mentoring. Among significant others, mentored individuals demonstrated greater”

- “Both SPM and PP participants reported high satisfaction with the mentoring program. Statistically significant improvements in perceived social support after mentoring were observed for the mentored group compared to WL participants; however, an increase in depressive symptoms was also observed. While significant improvements in social activity level and social network size were not found, a trend toward increased satisfaction with social life was present for mentored participants.”
| 57 pts had TBI, of which 30 successfully completed the programme. | suggests the merits of this type of community-based support. | community integration ($P = .03$) than the non-mentored control group. | Improvements in social integration scores were observed for active peer partners, but were non-significant. |

**Conclusions**

“Overall, findings suggest that mentoring can be beneficial toward achieving the goals of post-secondary education, employment and community independence for individuals with disabilities; specifically those with traumatic brain injury, spinal cord injury and other neurological disorders.”

The importance of individual peer support visits is supported by positive conversations with the patients and families who receive support.

The TBI peer support program significantly affects the lives of the peer supporters through a feeling of self-esteem.

Preliminary data suggest that peer support is a promising approach to enhancing coping for both individuals and their family members after TBI.

The program seems to have been associated with significant improvements in partner functioning in multiple key areas as compared to controls.

“Mentoring can be an effective way to benefit mood and healthy coping after TBI, and it can help to prevent maladaptive behaviours, such as substance abuse and behavioural dyscontrol, in the living situation.”

“Future research should address which components of education about recovery from brain injury and adjustment to living with such injuries might be most helpful to persons with TBI and their significant others.”

“Satisfaction ratings for the SPM program were uniformly high and selected positive findings encourage further investigation of social mentoring as an intervention to effect improvements in social integration. Small sample size and reduced “dosage” of mentor interactions were limitations of this pilot study.”
Figure

Records identified through database searching (n = 752)

Additional records identified through other sources (n = 1)

Records after duplicates removed (n = 495)

Records excluded using title / abstract (n = 459)

Full text articles assessed for eligibility (n = 36)

Full text articles excluded (n = 30)
  - Abstracts with insufficient information (n = 8)
  - Doesn’t fit model of 1:1 peer mentoring (n = 13)
  - Non-traumatic brain injury/no disability for participants (n = 5)
  - Conference abstract of included study (n = 1)
  - Systematic review citing included study (n = 2)
  - Conference abstract of ongoing study with results not yet analysed and published (n = 1)

Studies included in final analysis (n = 6)

Figure 1: Flow diagram of study selection process