

# A systematic review of lived experience and coping styles among survivors of traumatic brain injury (TBI)

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## Abstract

**Background & Objective:** Throughout recovery, patients with traumatic brain injury (TBI) demonstrate physical, functional, cognitive, and psychosocial problems. The aim of this article was to review the literature regarding the lived experience and coping styles among TBI survivors. **Method:** The review was guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement. The literature search was conducted using three different electronic databases, namely Scopus, CINAHL, and Ovid-Medline. In quantitative studies, a critical appraisal guide provided by Coughlan, Cronin and Ryan (2007) was used. Meanwhile, empirical studies of the qualitative studies were guided by the Joanna Briggs Institute (JIB) Critical Appraisal Tools for Reporting Qualitative Research. **Result:** There were 13 articles reviewed, four of them were quantitative studies and nine were qualitative studies. Most of the articles showed that TBI survivors faced problems in terms of emotional, behavioral, cognitive, and functional aspects, as well as quality of life. For the young TBI survivors, they have had to cope with academic challenges such as attention deficit and poor academic performance. For TBI survivors and partners, they also faced intimate relationship problems. Various coping practices were applied to regain their normal life. Some of the survivors used passive approach like avoidance and isolation. Some of the survivors applied religious coping methods to keep them feeling positive.

**Conclusion:** This review confirmed the different dimensions of difficulties that TBI survivors faced. There are limited Asian studies on this clinical problem where socio-cultural factors are important in the coping with the disabilities.

**Keywords:** Traumatic brain injury, lived changes, coping practices, experience

## INTRODUCTION

Traumatic brain injury (TBI) was referred as a 'silent epidemic' which remains a public health concern and represent the greatest contribution on global death and disability. There are estimated around 64 to 74 million new cases of TBI were reported in worldwide.<sup>1</sup> Centre of Disease Control and Prevention (CDC) reported during 2013 in the USA, almost 2.8 million of the 26 million injury-related emergency department visits, hospitalization and deaths were from TBI cases.<sup>2</sup>

There are many lived changes happen in people who suffer with TBI, which include cognitive changes<sup>3,4</sup>, functional changes<sup>4-7</sup>, health related quality of life<sup>8-9</sup>, self-identity changes<sup>3,4</sup> and others. Other than that, TBI survivors' reported person

with TBI may have problems with interpersonal, social, cognitive and physical after the injury.<sup>3,4,10</sup> Therefore, the person with TBI may use several coping practices to deal with it. Some of them may use religious and spiritual which can make them feel calm when connected with higher power<sup>11</sup>, they also may withdraw from the social world, tried to be positive in terms of having positive mindset, spirit and afford<sup>3</sup> and they also look for support from others.<sup>10</sup> It is important to focus on understanding how TBI survivors undergone their lives changes after trauma event and how they handle those changes.

This review focused on the lived changes and coping practices experiences among TBI population. Therefore, this work was aimed to analyse, summarise, and synthesise the relevant

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literature available. Both articles from quantitative and qualitative studies were included in this review. The literature review questions below were adopted to guide the literature review process. The review questions were: 1. What are the lived changes experienced undergone by TBI survivors? 2. How do they cope with the changes?

## METHODS

### *Literature search*

The literature search was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement to identify and extract all current available literature related to the topic. A systematic process for literature review search was beginning from August 2018 until October 2020. Three main databases were used in the systematic review, namely: Scopus, CINAHL, and Ovid MEDLINE, with the assistance of the librarian. Other databases have been used to search the articles but most of the articles related to this review were found in these three databases. In addition, these three databases were used because it was the prominent databases for healthcare field especially in nursing and allied health professional. These electronic databases also were employed to access the library databases and online search for nursing and medical journals. The search strategies were based on the Medical Subject Heading (MeSH) terms to identify the related literatures that referred to the two key components of the review topic:

1. People with TBI (the MeSH terms were used traumatic brain injury/ brain injury/ head injury).
2. The phenomenon of interest (the MeSH terms were used life experiences/ life changes/ coping).

The phrase searching and Boolean operator technique (using “OR” and “AND”) were employed to link all key components during the searching process in all databases. The full search strategy for all databases and screened all abstracts and title for inclusion was done by the first author. Meanwhile, the review of full texts for the potential eligible studies was done by two authors.

### *Study selection*

After a systematic review process done, 70 literatures were identified. Titles and abstracts for these 70 literatures were examined to determine the potential relevance to the objectives of this

study. The literatures were assessed based on several criteria, where the inclusion and exclusion criteria determined in this process were to ensure only related literatures are retrieved. First, regarding the timeline, a period of 20 years was selected (between 2000 and 2020) to examine the evolution of research and related publication. Only journal articles with empirical findings were selected, in which review articles, books, and conference proceedings were all excluded. To avoid any confusion and difficulty in translating, only literatures published in English were selected for the review. To maintain the focus of the review, only articles focused on lived changes and coping experience among TBI survivors were assessed, with the age of the survivor of greater than or equal to 18 years old was included. Studies on clinical trial and on children with TBI were excluded. Finally, only 13 literatures were included in this review. Therefore, a critical appraisal guide provided by Coughlan et al. (2007) was used to appraise quantitative literatures<sup>12</sup>, whereas the Joanna Briggs Institute Critical Appraisal Tools for Reporting Qualitative Research (2008) were used to appraise the qualitative literature in this review.<sup>13</sup> Figure 1 shows the flow of literature search strategy process, also known as the Systematic Review Flow Diagram.

## RESULTS

Out of the 13 studies, nine literatures were qualitative studies, while the other four were quantitative studies. The included literatures represented findings from seven different Western countries, which are United States of America (n = 2), Australia (n = 2), Norway (n = 1), United Kingdom (n = 3), Denmark (n = 1), Canada (n = 1), and New Zealand (n = 1). Meanwhile, findings from an Asian country is represented only by Malaysia (n = 2). The highest sample size for qualitative studies in this review was 40 participants, meanwhile 9 participants was the lowest. Therefore, the average sample size was 20 participants for qualitative studies. In quantitative studies, the highest sample size was 174 and the lowest was 29; thus, the average sample size for quantitative was 82 participants. Supplementary Table 1 exhibits the findings of lived changes and coping practices used by TBI survivors from previous literatures.

### *Lived experience changes after traumatic brain injury (TBI)*

Eight qualitative papers have discussed on the

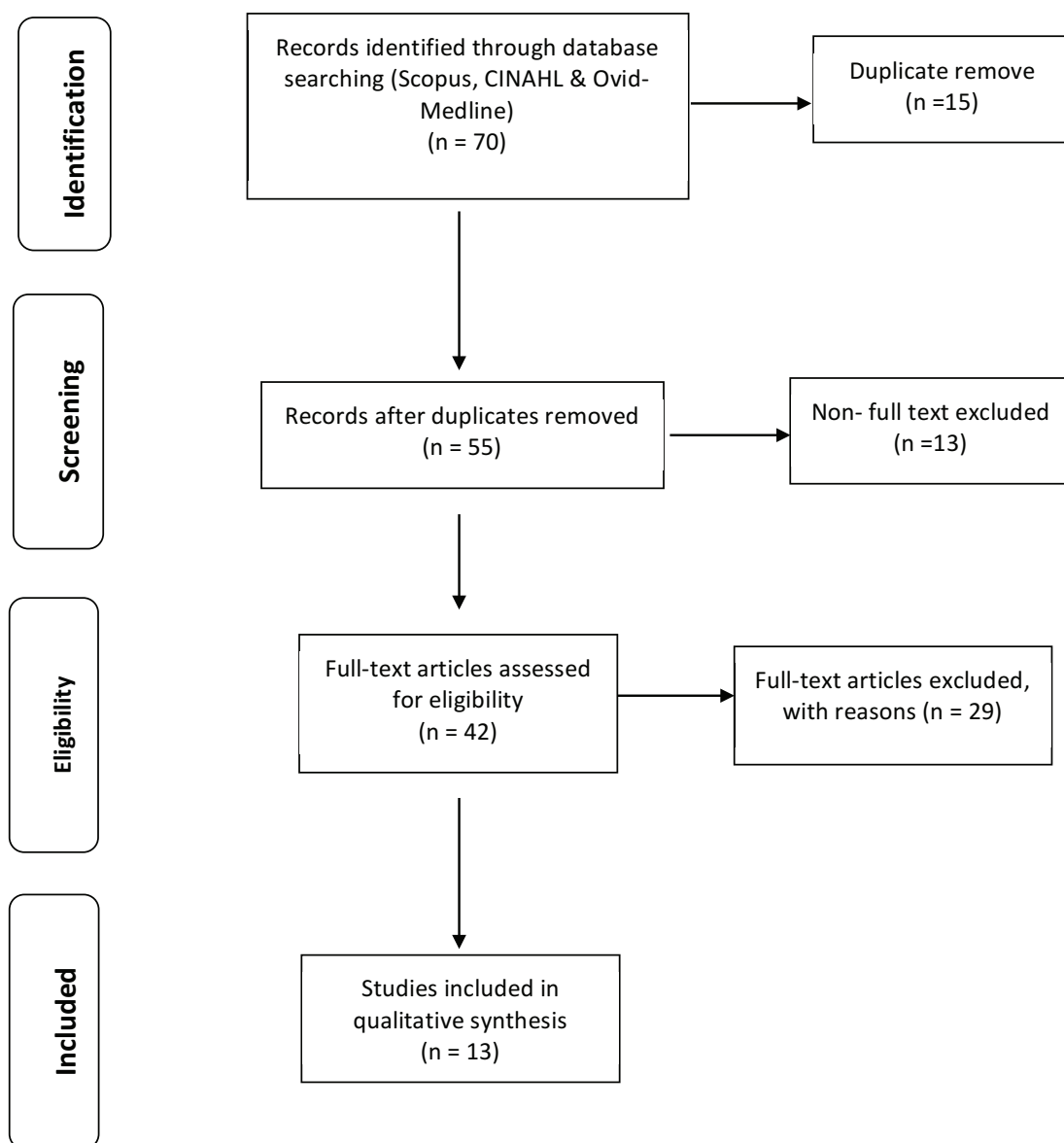


Figure 1. Study selection based on PRISMA guideline

lived experience changes of TBI survivors.<sup>3,4,10,14-18</sup> Most of the papers agreed with the possibility of TBI survivors having emotional, cognitive, behavioural and functional changes after trauma.

One study explored on the experience of return to work among TBI survivors.<sup>14</sup> Most of the participants have experienced increasing awareness on their difficulties related to their injury, fatigue, welfare benefit difficulties, rely on public transport which are too crowded for going to work and memory impairment. Besides, participants also expected to return to work immediately and wanted to gain pre-injury life faster. But, faster return to work resulted in failure

and slow return to work was more successful which means TBI survivors need more preparation before return to work. Therefore, the researcher suggested occupational therapy to help the TBI survivor by giving more detailed advice and support regarding the consequences of return to work and when is the best time to return to work.

Another study has done on nine participants to explore on the social relations of self-identity while focusing on the emotional experience of male survivors.<sup>3</sup> Prior to the interview, the participants were screened for depression, anxiety, and post-traumatic stress disorder (PTSD). Results reported that five of them were free from

depression, anxiety, and PTSD: three participants scored mild-to-moderate range of depression and moderate-to-severe range of anxiety. This result was related to fatigue and physical injury sequelae. Findings on TBI survivors' experience showed they have a sense of abnormality in terms of stigmatised opinion that they believed to be held by others, altered role within family, being treated differently by others, shame towards others due to the loss of intelligence, and negative self-comparison with their previous lifestyle.

A study in New Zealand revealed that participants have described TBI to be profoundly disruptive of their daily lives because of ongoing fatigue, cognitive difficulties in terms of handling their daily routine and financial to get back to normal, struggle to understand the sequelae of TBI, and the feeling of being disconnected from their previous lifestyle.<sup>10</sup> The study about needs and deficit needs in USA revealed that the majority of the survivors needed acknowledgement on how brain injury affects their family and social system.<sup>4</sup> Furthermore, it was learnt that participants needed patience and support in the form of professional help, advocacy, information, community resources, family, and friends to face the lived experience of lifestyle changes. Another qualitative study was done in Denmark aimed to provide an understanding of the lived experience of rehabilitation in an adult with TBI from hospital discharge up to four years post-injury.<sup>15</sup> The results reported some participants felt that the transition from hospital to home was challenging due to cognitive and physical disabilities. These deficits have led to frustration; however, for some participants, they perceive this injury as a symbol of new beginning. In addition, participants expected new roles as patients and family caregiver. In most cases, the family became the voice and advocate for the participant. The transition from hospital to home is a stressful and demanding phase, thus, TBI survivors become dependent on family caregivers. The survivors also expressed a need for post-hospital follow-up to clarify their situation and ensure the right rehabilitation plan is coordinated for them.

A regarding the transition from hospital to home was conducted in Australia.<sup>16</sup> It was found that transition experience is characterised by a desire to return to normalcy and a changed perspective on life by accepting the change of priority. The patient's desire for normality includes being independent, having a good relationship, being able to carry out activities much like they have in their life pre-trauma, and having good health. For

a changed life perspective, they learn to accept and alter their priority based on their new life. Some of the survivors were able to accept their new life, while, some of them are still learning to adapt to the changes. That being said, they also showed appreciation towards the support they received from others.

One study has explored the experiences of intimate relationship for both TBI survivors and their partners.<sup>17</sup> Some couples reported TBI survivors being changes to different person compared than before the injury. Moreover, the participants revealed sexual dysfunction, role changes and communication problems also one of the barriers for them. For the factors that give them strength for their relationship were being understanding for their partner, having good pre-injury relationship, TBI survivors feel grateful for survive, having strong support from social and family, having good spirituality and have good coping skills. This study revealed a good start for partner's relationship between TBI survivors and their partner, the researcher can explore in detail how their relationship going on after the trauma. It is a good opportunity for future study to study on this topic, because it will reveal more finding based on different view such as culture, religion, race and ethnicity.

A study of the changes in spiritual beliefs after traumatic disability revealed the survivors have greater awareness of the self which is, the survivors become more appreciate on themselves, a change in their view of their own independence, a sense of purpose in life, a greater awareness of their own mortality, new understanding of trust, loss of significant relationships, greater appreciation and closeness with others and the world, and deeper understanding of other disadvantaged groups.<sup>18</sup> However, in this study, the sample was taken from those who experienced traumatic disabilities, which include spinal cord injury and TBI survivors. Therefore, the results may have some bias because the sample was not retrieved from solely TBI survivors.

There are four quantitative studies that discussed lived changes of TBI survivors.<sup>19-22</sup> One study in North of Malaysia, showed that 25% of the participants were diagnosed with depression and 14% were diagnosed with anxiety.<sup>19</sup> The only factor that is significantly associated with depression was the duration of TBI. Meanwhile, the mechanism of trauma was the sole significant factor for anxiety. It is suggested that future research includes investigating factors of religious participation, family and social support, perception

of symptoms, and functional capacity related to cultural differences, all of which may contribute to the difference in the psychiatric outcome of TBI. Another study done in United Kingdom, among 29 participants with TBI showed emotional changes, depression, and lower rating for self-concept (by participants themselves) in the present life.<sup>20</sup> There was a positive association between the perceived self-changes with depression and grief. The study also showed that TBI survivors may have depression and grief because of their personal identity changes.

Meanwhile, in Australia a study had focused on pre- and post-injury coping styles in the first three years after TBI and the effect they have on psychosocial, emotional, and quality of life (QOL) one year following TBI.<sup>21</sup> Results revealed that higher use of non-productive (i.e., emotion focus style by passive reaction or avoidance strategies) coping style for preinjury was predicted high use of non-productive coping, which lead to higher anxiety, and lower psychosocial functioning one-year post-injury. Furthermore, it was reported that TBI survivors have lower QOL one-year post-injury. Additionally, the above-mentioned study has reported on the greatest psychosocial impairment in occupational activities, changes in interpersonal relationship (e.g. spouse, family, friends and other people), and independent living skills (e.g. changes in social skills, personal habits and daily living activities). The majority of the participants reported having depression and anxiety scores in the normal range at one-year post-injury. The finding emphasizes to facilitate the survivors to use productive coping mechanism to promote long-term psychosocial outcome.

Another study was conducted in the USA among college students who experienced TBI.<sup>22</sup> The outcomes reported that the college students who experienced TBI have memory impairment, difficulty with academics, organisational difficulty, problem making decisions, and impaired attention. For the psychosocial effects after injury, three-quarters of the sample reported symptoms of anger and depression. For the relationship between the physical, cognitive, and psychosocial effects after TBI; there was a significant positive correlation between the injury effect and academic challenges which are having memory problems, academic difficulties, get nervous before test getting overwhelm in class and others did not understand their problems.

### *Traumatic brain injury (TBI) survivors coping strategies with lived changes after trauma*

The coping mechanism post-trauma is a part of the rehabilitation process undergone by TBI survivors. In fact, every person may apply different coping strategies. Some TBI survivors might obtain support from others to help in their new life post-trauma,<sup>10</sup> while others may think positively and look forward to starting a new life and learning to accept the changes.<sup>3,10,16</sup>

TBI survivors may apply problem-focused, emotion-focused, and avoidant coping mechanism in their adjustment to home life and activities of daily living.<sup>4</sup> It includes being more patient, attempting to reduce any stimuli that may lead to their emotional effect, using any source of memory aid to avoid memory deficits, and having small discussions with their loved ones regarding their personality changes. Moreover, they also involve in support group. In the support group, they will share their experience and TBI information with others survivors.

Another coping practice was an active or passive approach to regain a normal life after injury.<sup>16</sup> Those who apply the active approach will express feelings of frustration and engage in a fight to regain control over the choice influencing their future life. However, in passive approach, survivors tend to wait for things to return to normal despite feeling frustrated, sad, or depressed with their current condition.

Coping styles may be different based on religious practice and ethnicity. A study done in Malaysia reported that psychological coping strategies were used to cope with a traumatic event, especially on motor vehicle accident (MVA) victims.<sup>23</sup> For psychological coping, most of them tend to have positive thinking and rationalisation of what had happened to them. They also have good support from their family members after the trauma and most of them will practice common spiritual strategies, such as prayer and reciting Quranic verses to reduce their post-traumatic stress. Because of the limited study on TBI survivors' coping style in local setting, the researcher used this finding as the baseline data for the coping strategies used by MVA victims. This is because most TBI incidents in local setting come from MVA cases.<sup>7,24</sup>

## **DISCUSSION**

The main data collection procedure in qualitative design was by interview, this can be a challenging process. This is partly because the TBI survivors



may have emotional and cognitive changes, fatigue and distractibility that may affect the interview process. Some of the authors revealed they will stop the interview if they noticed the participants shown any distractibility sign, fatigue, emotional and cognitive changes.<sup>3,4</sup> A good time management and a well-prepared plan is particularly important in interview with this group of patients.

In terms of study setting, eight studies involved participants from the hospital, rehabilitation unit and TBI organisation. Only one study recruited the participants from college. Different study setting may report different findings. A study was performed on college students to investigate their academic challenges.<sup>22</sup> The result may differ according to the different courses of study. For example, a science stream TBI student may have different challenges in term of their subjects, in-class experience and assignments compared to those in non-science stream. Therefore, future study may explore the challenges of the survivors from the different academic fields.

In the recruitment process, several studies have provided detailed information<sup>4,15,16,18,19,21-23</sup> except for two.<sup>3,10</sup> The authors have provided details on how the participants have been approached, either face-to-face, by email or telephone. The objectives of the study were clearly explained to the participants and clear explanation was provided on the number of participants that have refused to participate in their study, including the reason for dropping out. For ethical aspect, most studies have provided the details.<sup>3,15,16,19,21-23,25</sup>, except for four studies.<sup>4,10,17,18</sup>

TBI often result in a prolonged recovery phase, thus, it may have impact on partner relationship; however, only one study have explored this aspect.<sup>17</sup> For this issue, a good communicating and interviewing skill is particularly essential to ensure that the researcher can acquire adequate information. This include a good rapport with the patients. This is because not all participants will willingly share their experience on their intimate relationship. As this is an aspect where religious, cultural and belief practices are important, it is hoped that there will be more future studies from different culture and religious background.

This review has provided the review on both qualitative and quantitative research finding on lived changes and coping strategies used by TBI survivors. The majority of TBI survivors are struggling to attain their sense of normalcy in life. The crucial phase in their post-injury life is within the recovery process. It will be beneficial to the healthcare provider to have

an insight of the patients' lived experience and coping practice. Most of the studies have been conducted in Western countries, while only one study was done in Malaysia, which focused on the psychological symptoms that portrayed TBI survivors' experience of depression and anxiety post-injury. Meanwhile, another study revealed that motor vehicle accident victims have adopted psychological, social, and spiritual coping strategies to reduce post-traumatic symptoms disorder (PTSD) but the result was not specific towards the TBI survivor's population. Therefore, it is hoped that more future studies on TBI survivors lived changes and coping practices experiences from different community and socio-cultural settings will be performed.

It is hoped that the result of this review will improve the understanding of our healthcare provider and the community on the challenges facing the TBI survivors. Hopefully it will reduce the negative perception toward TBI survivors, initiate more support groups for these patients and improve the related community nursing services.

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## DISCLOSURE

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Conflict of interest: None

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Supplementary Table 1: Finding of the included studies

Type of Research study	Year	Authors & country	Research Objective	Recruitment Strategy	Data Collection Method	Finding
Cross-sectional study	2018	Abdullah, Ng & Sidi (MALAYSIA)	<p>Objective:</p> <ol style="list-style-type: none"> <li>To investigate the rate of depression and anxiety disorder among TBI patients in Malaysia</li> <li>To determine the socio-demographic and clinical factor associate with depression and anxiety in the TBI population in Malaysia.</li> </ol>	<ol style="list-style-type: none"> <li>Participants were recruited from neurosurgery clinic of Hospital Pulau Pinang, tertiary hospital in northern of Malaysia.</li> <li>Samples were recruited via consecutive sampling (n=101).</li> <li>During the recruitment of samples, samples were tested for Karnofsky Performance Scale Score, which to exclude the poor functional status and greater physical disability which can affect their emotional status and ability to complete the assessment.</li> <li>The sample was recruited after 3 months post injury because most patients were discharged after 3 month post injury.</li> </ol>	<ol style="list-style-type: none"> <li>Demographic and clinical data were collected from sample database.</li> <li>The researcher was trained to use structured clinical interview for DSM IV and administer it to SCID-I.</li> <li>But the detail where the data was collected is not clear. The researcher doesn't mention either they collect the data at rehabilitation unit or at participants' house.</li> </ol>	<ol style="list-style-type: none"> <li>25% were diagnosed with depression disorder.</li> <li>14% were diagnosed with anxiety (9% were PTSD).</li> <li>Duration of TBI (&gt;1 years) is the only factors associated with depression.</li> </ol> <p>Trauma mechanism is the only factor associated with anxiety. With others trauma or assault was the larger prevalence of anxiety.</p>
Quantitative Prospective retrospective observational study.	2018	Tverdal <i>et al.</i> (USA)	<p>Objective:</p> <ol style="list-style-type: none"> <li>To describe the discharge process for TBI patients from trauma hospital</li> <li>To know patient experience and satisfaction with care transition.</li> </ol>	<p>Recruitment strategy was clear. Participants were recruited from Oslo University Hospital (OUH) (n=74), Participants were stratified into 3 groups which are emergency room, admission stratum and ICU stratum.</p>	<p>Demographic data and injury characteristic were extracted from the participants' database. Participants database was accessed in discharge planning process and the evaluation was conducted by study nurse and physician. The same persons performed 6 month follow up interview to know participants experience and satisfaction. But the 6 month justification was not clear; either 6 months were taken from admission date or discharge date.</p>	<ol style="list-style-type: none"> <li>One-third of participants were not involved in discharge process and information regarding discharge summaries was often insufficient.</li> <li>Participant's involvement in care transition and co-ordination of care were significantly associated with overall satisfaction, and quality of care transition.</li> <li>Participants with more severe showed lower satisfaction and quality of care transition.</li> </ol>



Quantitative study.	2014	Gregorio, Gould, Spitz, van Heugten Ponsford (AUSTRALIA)	Objective: 1. To examine the influence of self-reported pre-injury coping with psychosocial functioning, emotional functioning, and quality of life at 1 year post-TBI	Recruitment strategy was clear. Participants were recruited from consecutive TBI admission to a rehabilitation hospital between August 2005 and August 2010 (n=174).	Participants were interviewed at 5 time points (face to face or telephone), T0 is during inpatient admission after TA or soon after discharge, T6 after 6 months, T12 after 12 months, T24 after 24 months and T36 after 36 months. Demographic data were collected at T0. The used of coping style was access at each time point. Measure of QOL, depression and anxiety were completed at T0 and T12, whereas measure of psychosocial functioning was administered at T12.	<p>1) High preinjury use of nonproductive coping style predicted high use of nonproductive coping, more anxiety, and lower psychosocial functioning at 1 year post-injury.</p> <p>2) Increase use of nonproductive coping and decrease use of productive coping predicted poorer psychosocial outcome at 1 year post TBI.</p> <p>3) Preinjury coping style have positive association with postinjury coping style.</p>
Quantitative study.	2008	Kennedy, Krause & Turkstra (USA)	Objective: 1. To document academic challenges (studying, in-class experience, time management & psychosocial aspect) reported by adults with TBI. 2. To investigate the relationship between these challenges and the physical, cognitive and psychosocial consequences of TBI.	Recruitment strategy was clear. Participants were recruited from an university (University of Minnesota) (n=35).	Participants were asked to answer the survey that can access online (consist of 8 set of questions). Only participants who give authorization to sign legal documents were proceed to include in the analysis.	<p>1) For the general effect of TBI. Majority students reported to have experience fatigue, impairment of leg (which effect their walking), dizziness and physical impairment of arm/hand (which effect their writing)</p> <p>2) For cognitive, the higher report are having memory problem and difficulty with academics.</p> <p>3) For psychosocial, the higher report are anger and depression.</p>

<p>descriptive phenomenology</p>	<p>2019</p> <p>Beaulieu (UK)</p>	<p>To explore on TBI survivors lived experiences on return to paid work; what is the barriers and success factors for that.</p>	<p>Snowball sampling, 16 participants were recruited and consented after they see the poster on headway UK.</p>	<p>1. The participants were interviewed with unstructured interview. 2. The researcher started the interview with open ended and triggered question. 3. Researcher preconception idea were bracketed using reflective diary and reflexivity.</p>	<p>There were 6 themes from this study.</p> <ol style="list-style-type: none"> <li>1. Coping with ongoing difficulties- awareness, cognition, memory difficulty, welfare benefits and transportation.</li> <li>2. Expectation and timing of return to work- they expected the fastest possible return to work and pre-injury lifestyle.</li> <li>3. Workplace colleagues' reaction- they experience some of their colleagues give support and some have negative impression toward them.</li> <li>4. Things that help- they shared they get practical and emotional support from social, healthcare and family.</li> <li>5. Change and return to work options- only seven participants return to their pre-injury work. The rest, they had different work.</li> <li>6. Feeling of success- they success to return to their work and pre-injury life.</li> </ol>
<p>Qualitative explorative design, hermeneutical phenomenology.</p>	<p>2017</p> <p>Heidi J. Graff <i>et al.</i> (DENMARK)</p>	<p>Objective: To provide an understanding of the lived experience of rehabilitation in adults with TBI from hospital discharge up to 4 years post-injury.</p>	<p>The recruitment strategy was clearly explained. The participants were recruited 4 years back (from admission date), but the study's duration was 6 months. The inclusion criteria were clear. The interview was done by phase based on severity of injury and concern about outweighed by the risk of interviewing prematurely before the participant had completed the rehabilitation trajectory. The cutoff age was 60 to include individual who likely to return to work.</p>	<p>1. The interview have 3 parts on rehabilitation on the acute and sub-acute phase, stable has end return home phase. 2. The interviews have done by first author. 3. The privacy and disruption were ensuring during interview. 4. Interview done between 30-60 mins. 5. Field notes were written during and immediately after the interview.</p>	<ol style="list-style-type: none"> <li>1. 3 themes; a new life, family involvement &amp; rehabilitation impediments.</li> <li>2. A new life theme explained how TBI could induce participants to reassess their values as the injury indicated a new beginning. Family involvement revealed how participants dependent on the family caregivers as the family assumed the responsibility for ensuring the best rehabilitation. Rehabilitation impediments explained lack of transparency regarding rehabilitation options, the need for follow-up and for age-appropriate rehabilitation.</li> </ol>

Qualitative study	2017	McPherson <i>et al.</i> (NEW ZEALAND)	<p>Objectives:</p> <ol style="list-style-type: none"> <li>To explore what helps and hinders recovery and adaptation after disabling TBI.</li> <li>To make recommendations for improving the service responsiveness.</li> </ol>	<p>Participants are involved in this study were (n=40) from TBI survivors &amp; (n=22) from significant others. The recruitment based on 6 months post injury and includes all TBI severity. Purposeful sampling was applied to seek rich and thick data.</p> <p>But the detail of recruitment process didn't clearly explain. The author only states the recruitment from population-based longitudinal epidemiology study and expands the recruitment via TBI service provider and patient support organizations in the region.</p>	<p>The author used semi structured interview using prompts to focus the interview into 4 domains. These 4 domains will answers the research objective of this study.</p> <p>But the detail how the data was collected was unclear. (e.g instrument use for interview, where the interview done, transcript return to the participants or not)</p>	<p>There are 5 themes related to recovery and adaptation after TBI.</p> <ol style="list-style-type: none"> <li>Keeping up with life</li> <li>TBI means for and to me</li> <li>Disconnection and connection</li> <li>When to challenge and when to accept</li> <li>Being looked out for someone to help drive the process as valued support</li> </ol>
Exploratory qualitative design – In depth interview.	2016	Rafidah Bahari <i>et al.</i> (MALAYSIA)	<p>Objective:</p> <p>To explore the coping strategies used by MVA victims, mainly focused on the psychological, social &amp; spiritual approach to deal with post-traumatic stress symptoms.</p>	<p>The participants were taken from quantitative study. Only 29 participants eligible to participant in qualitative study. During interview, up till 9 participants had given saturated data. Thus, for this study the participants was (n=9). All the participants were from A &amp; E UKMMC.</p>	<p>1. The interview was led by main researcher.</p> <p>2. There are no anyone else presented during the interview session, only researcher and participants.</p> <p>3. The researcher ensures the privacy and minimizes the destruction during interview.</p> <p>4. Purposive sampling was applied.</p> <p>5. Semi-structured interview was developed based on the study's objective.</p> <p>6. Pilot study was done on 3 participants to get their feedback on interview protocol.</p>	<p>1. Most of the participants reported still have post trauma stress (PTS) symptoms e.g altered mood, anger alteration in cognitive.</p> <p>2. Most of the do not aware it is symptoms of mental health problem. So, they tend to use other coping strategies which are psychological, social &amp; spiritual.</p> <p>3. 2 themes derived from psychological coping which are cognitive &amp; behavioral coping.</p> <p>4. 3 themes derived from religious coping which are use of religion/spiritual to make sense of PTS, to reduce general distress and to handle specific symptoms.</p> <p>5. Strong social support help them to reduce PTS symptoms.</p>

<p>Phenomenological design</p>	<p>2016</p>	<p>Adams &amp; Dahdah M. (USA)</p>	<p>Objective:                      1. To explore the need and deficits of adult TBI and primary caregiver.                      2. To identify their coping &amp; adaptive strategies.</p>	<p>1. The recruitment strategy was clearly explained.                      2. The TBI patient was (n=11) and primary caregivers were (n= 6).                      3. The invitation to join the study was recruited under TBI support group in Dallas/Fort Worth area in USA, and the invitation was posted in two online TBI organizations (BTF &amp; BI-IFEA).</p>	<p>1. The interview method was clear. Semi structure interview was developed to answer the research objective.                      2. Interview guide was provided in this article but the author not mention about pilot study.</p>	<p>1. There are 4 theme was focused from this finding which are need, deficit, coping &amp; adaptive strategy used and suggestion to MHP.                      2. Both TBI and primary caregiver needs were patience, understanding and support.                      3. The self-report deficits were cognitive, physical, emotional &amp; personality changes.                      4. Both TBI and caregivers use several coping strategies to minimize the self-deficits.                      5. Participants suggested to provide counseling and educate them about squeal of TBI.</p>
<p>Qualitative study - In depth interview</p>	<p>2015</p>	<p>Anita Freeman, Malcolm Adams &amp; Fiona Ashworth (UK)</p>	<p>Objective:                      To explore the lived experience of male survivors of TBI in relation to perceived changes in their personal and social identity.</p>	<p>The participants were recruited from Oliver Zangwil Center for neuropsychological Rehabilitation (OZC) (n=9). The flow of the recruitment process was unclear which means, the author just directly stated they recruit 9 participants.</p>	<p>1. The interview was done by main researcher.                      2. There only researcher and participants involve during interview.                      3. The privacy and disruption were ensuring during interview.                      4. Pilot study not mention in this articles.                      5. The duration of the interview around 58 min.                      6. How many the interview was carried out also not mention.                      7. After the interview, debrief was done to allow participants to reflex and give feedback to the researcher.</p>	<p>A. The men experience's following TBI                      1) a sense of abnormality                      2) a hidden injury                      3) others treat me differently                      4) the old-me and new-me                      5) social relatedness of emotion                      B. The men's responses to their experience                      1) self-criticism                      2) needs to be as others want me to be                      3) withdrawal from social world                      4) resolution in positive growth</p>

In depth interview were done to answer the research questions which are:

1. How do survivors of TBI experience changes in the self and identity in relation to their social context following TBI?
2. What is the nature of the emotional experience of the self in the social world for male survivors of TBI?

<p>Qualitative study - In depth interview</p>	<p>2015</p>	<p>Anita Freeman, Malcolm Adams &amp; Fiona Ashworth (UK)</p>	<p>Objective: To explore the lived experience of male survivors of TBI in relation to perceived changes in their personal and social identity.</p>	<p>The participants were recruited from Oliver Zangwil Center for neuropsychological Rehabilitation (OZC) (n=9). The flow of the recruitment process was unclear which means, the author just directly stated they recruit 9 participants.</p>	<ol style="list-style-type: none"> <li>1. The interview was done by main researcher.</li> <li>2. There only researcher and participants involve during interview.</li> <li>3. The privacy and disruption were ensuring during interview.</li> <li>4. Pilot study not mention in this articles.</li> <li>5. The duration of the interview around 58 min.</li> <li>6. How many the interview was carried out also not mention.</li> <li>7. After the interview, debrief was done to allow participants to reflex and give feedback to the researcher.</li> </ol>	<ol style="list-style-type: none"> <li>A. The men experience's following TBI             <ol style="list-style-type: none"> <li>1) a sense of abnormality</li> <li>2) a hidden injury</li> <li>3) others treat me differently</li> <li>4) the old-me and new-me</li> <li>5) social relatedness of emotion</li> </ol> </li> <li>B. The men's responses to their experience             <ol style="list-style-type: none"> <li>1) self-criticism</li> <li>2) needs to be as others want me to be</li> <li>3) withdrawal from social world</li> <li>4) resolution in positive growth</li> </ol> </li> </ol>	<p>In depth interview were done to answer the research questions which are:</p> <ol style="list-style-type: none"> <li>1. How do survivors of TBI experience changes in the self and identity in relation to their social context following TBI?</li> <li>2. What is the nature of the emotional experience of the self in the social world for male survivors of TBI?</li> </ol>
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Qualitative explorative design	2013	Nalder <i>et al.</i> (AUSTRALIA)	Objective: To examine the lived experience of TBI survivors during 1 <sup>st</sup> 6 months following discharge from hospital.	The recruitment strategy was clearly explained. The participants were from phase 1 which in quantitative study in this study (actually this study does mixed method, but this paper focus on qualitative only).	<ol style="list-style-type: none"> <li>1. The interview conducted with participants on average 9 months following discharge from hospital.</li> <li>2. The author has key question during the interview. "Can you tell me about what as happened in your life since leaving hospital?".</li> <li>3. The interview had done face-to-face or telephone.</li> <li>4. The first author, occupational therapies and doctoral candidate were conducting the interview.</li> <li>5. The privacy and disruption were ensuring during interview.</li> <li>6. Interview done average 92 min in duration.</li> </ol>	<ol style="list-style-type: none"> <li>1. 2 themes; wanting normality and changed perspective on life.</li> <li>2. Participants wanted to regain a sense of normality life, in term of independence, relationship activities and health.</li> <li>3. The participants responded into active and passive way in their lived changes.</li> <li>4. Active way is they are expressing feelings of frustration and being engaged in a fight to regain control over their life.</li> <li>5. Passive way is waited for things to return normal despite feeling frustrated, sad and depressed with their present.</li> <li>6. For 2<sup>nd</sup> theme, it have two ways, having to accept change and altered priorities.</li> </ol>
Grounded theory approach	2011	Gill <i>et al.</i> (UK)	To explore the experience of intimacy of TBI survivors and partners.	Participants were recruited at both Chicago (12 couples) and Houston (6 couples) project site. The recruitment process were done via announcement distributed via a brain injury program, support groups, advocacy organization and rehabilitation center.  Total participants were 18 couples.	<ol style="list-style-type: none"> <li>1. Interviewed was done by lead investigators at each site.</li> <li>2. The interview was separate for both participants and their partner.</li> <li>3. Open ended, semi structured and in-depth interview was conducted.</li> <li>4. The interview guide was generated from the literature review and approve by an institutional review board.</li> </ol>	<p>There are 2 main themes which are barriers to intimate relationship and factors related to relationship strength.</p> <ul style="list-style-type: none"> <li>• Barriers to intimate relationship</li> </ul> <ol style="list-style-type: none"> <li>1. Participants report due to physical, cognitive and emotional changes, it affects their intimate relationship.</li> <li>2. Communication also one of the barriers in their relationship. They can spell out their feeling due to cognitive and emotional changes.</li> <li>3. Some survivors experience separation from their partner.</li> </ol>

- Factors strength the relationship
- 1. Accepting their partner unconditionally.
- 2. Having good communication also help in strengthening their relationship.
- 3. Support from family and friends also help.
- 4. Spirituality and god coping skill were the factors help in the relationship.

Qualitative study	2000	McColl <i>et al.</i> (CANADA)	Objective: To discover the effect of sudden-onset disability on spirituality, specifically, to investigate changes following the onset of disability in spiritual concepts and to outline a theoretical framework consisting of relationships with self, others, the world and a supreme power.	The recruitment was done on 16 participants (spinal cord injury =8) (ABI=7) (both=1). Participants were referred to the study from the regional Rehabilitation Service at St. Mary's of the Lake Hospital, in Kingston, Ontario, Canada. The flow of recruitment was clearly explained.	<ol style="list-style-type: none"> <li>1. The interviews have done by trained interviewers with experience in pastoral care and rehabilitation.</li> <li>2. The privacy and disruption were ensuring during interview.</li> <li>3. Pilot study doesn't mention in this articles.</li> <li>4. The duration of the interview was not mentioned.</li> <li>5. How many the interview was carried out also not mention.</li> </ol>
				5 themes; awareness, closeness, trust, purpose and vulnerability. 11 out of 16 experience significant loss or gain faith (2=loss, 7=gain, 2=both).	