

Protocol: Mapping review of storytelling as an intervention in traumatic brain injury rehabilitation

Review title

Storytelling as an intervention in traumatic brain injury rehabilitation – a mapping review

Working group

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Background

The inspiration for this review is based on the ideas related in the book *Who Am I Now? Using Storytelling to Accept and Appreciate Self-Identity after Traumatic Brain Injury* (2020) by Lethan Candlish, a researcher on this project (Candlish, 2020). In his book, Candlish presents an argument, using original research and examples from his own experiences, of how storytelling can help a survivor create and understand a continued sense of self-identity after TBI.

Storytelling as a method of rehabilitation after Traumatic Brain Injury (TBI) is becoming recognized as a productive tool that assists survivor-participants in the interpersonal recovery process. Although there is still relatively little research done into how this works, a qualitative synthesis by Kate D’Cruz, Jacinta Douglas and Tanya Serry (2019) suggests that the qualitative studies in this field show that a survivor expressing his or herself using a narrative technique (storytelling, written narration, poetry, photography and song) positively affects their experience with self-identity. As expressed in their review (p994), “Personal narrative approaches emerge as a positive experience for persons with TBI with an overall theme of ‘building strengths-based identity’”.

This qualitative synthesis is insightful for understanding the overall positive experiences by participants and the elements of these experiences, but the focus on qualitative synthesis necessarily focuses on TBI survivors’ experiences of these approaches, rather than the detail of the approaches themselves. Questions remain about the range of specific interventions or approaches have been documented and what underlying theories they draw on, details of how

these are structured, the specifics of the key elements of the approach and how they are operationalised, and to what extent the methods meet the definition of 'storytelling' as opposed to narrative therapy (with storytelling involving creative process and performance - see below). While it is unlikely that there are currently sufficient controlled trials to test efficacy of these types of interventions, efficacy is also a question that the current research team are interested in exploring.

The overarching interest of the review team is to investigate how various forms of "storytelling", as defined below, can affect questions concerning self-identity after TBI. Uncertainty and questioning concerning self-identity is an experience that often occurs after TBI (Levack, Kayes, & Fadyl, 2010), and the above discussed qualitative synthesis confirms the centrality of self-identity in storytelling experiences. However, for the purposes of an inclusive initial mapping review, we will not restrict our inclusion criteria to self-identity related outcomes.

Review question

The objective of this review is to systematically map the literature reporting on studies that have investigated storytelling as an intervention in traumatic brain injury (TBI) rehabilitation or recovery.

Our specific questions for the review are as follows:

1. What types of studies have been done that investigate storytelling as an intervention for survivors of TBI?
2. What is the timing of storytelling interventions in relation to a) stage of recovery and b) other rehabilitation?
3. What are the underlying theories that structure storytelling interventions in TBI?
4. What outcomes are hypothesized as a result of a storytelling intervention and how are they measured?
5. What are the timeframes and/or stages of intervention documented?
6. What methods of narrative creation and storytelling are used in TBI rehabilitation and recovery studies (including how guided the creation is)?
7. What are the modes of delivery and performance of the storytelling?
8. What evidence gaps exist in the research on storytelling as an intervention after TBI?
9. What recommendations for research or intervention development can be derived from the current literature in this area?

Participants/population

Population

We will include studies involving survivors of Traumatic Brain Injury (TBI), defined by Menon et al. (2010, p1638) "...as an alteration in brain function, or other evidence of brain pathology, caused by an external force."

We will exclude studies that focus on people living with the effects of other types of acquired brain injury (ABI), such as stroke, brain tumor, or other neurological disease because TBI often

prompts different social understandings and responses (e.g. dramatized as a 'tragic accident' or minimized as a 'bump on the head') compared to other forms of ABI, and we considered the social responses to the condition to be relevant and important when it comes to storytelling. We will include studies focused on survivors of TBI and that also include other groups of participants, those who are not survivors of TBI, as long as either: 1) 10% or more participants are survivors of TBI; and/or 2) the results of the study are clearly organized so that we can extract the data concerning only the participants who have survived TBI. If the study has 10% or more participants with TBI but indicates that the TBI participants had a markedly different experience or outcome to other participants and the details of this experience or outcome are not explicated in the results, we will exclude the study.

We will include information from all study participants, regardless of socio-economic status, employment, or age; this includes studies of children who have survived TBI, and we are curious as to whether there is more aptitude for employing storytelling for children due to lower social inhibition around story, play and performance.

Intervention / Phenomena of interest

We will include any studies investigating the relationship of storytelling to a person healing after TBI. In his book, Candlish defines the final stage of storytelling as "...a performance art where a performer, the *storyteller*, presents a spoken narration that relates a story to an audience." (Candlish, 2020, Introduction, p9) To refine that definition, "spoken" is not limited to verbal, auditory narration but could also involve written essays, song, a shared sign language, creative dance or movement, or other forms of creative expression – what is necessary is being able to communicate a narrative to a live audience. This "audience" does not necessarily mean a large and/or public audience. The audience could be one trusted counselor, family member, or friend, but what is important is that the audience person or persons are prepared to listen and recognize that the storytelling is a presentation (rather than an exchange) until after the storyteller/survivor has completed the performance. This is so the storyteller/survivor can fully relate their experience while witnessing the audience's reaction to the storytelling.

A key purpose of the mapping review is to investigate the various ways in which storytelling after TBI is conceptualized and operationalized. As such, inclusion criteria will recognize various methods of storytelling as self-expression therapy that occur after TBI. The inclusion criteria for the intervention are 1) there is some narrative element, 2) that there is a process of composing the story, which may include a relational process with a facilitator, and 3) that time and thought have been dedicated to the composition and rehearsal of the piece in preparation for some sort of eventual performance of the work. By this definition, the story to be told is a metaphorically "polished" piece of art as opposed to a work that is thrown together in a relatively short time, or told in a very informal way e.g. to a therapist in the course of therapy. While great art can come in an instant, the review authors are interested in the effects for survivors of TBI of the process of introspective work and research dedicated to creation of a storytelling project. To ensure capture for the review, we will include studies that look at *any form of creative, narrative self-expression by survivors of TBI about the experience of recovery*, including but not limited to: guided autobiographical writing, song composition, series of visual art pieces, creative writing, poetry, and creative movement or dance.

While this idea of using storytelling as a tool in recovery has some similarities with narrative therapy in terms on constructing a narrative, they focus on different goals; in brief, while narrative therapy seeks to reconstruct a person's story and/or create an alternative storyline that assists with therapeutic goals, storytelling is focused on forming a coherent storyline that was previously absent in a survivor's conscious experience. In storytelling, the 'rehabilitation value' of the *narrative itself* is less important. What is important is the process of creating and performing the story about what has happened. Studies investigating narrative therapy rather than storytelling will be excluded from the review.

Comparator(s)/control

We will include experimental studies that compare storytelling as defined above with other creative interventions, usual care or no intervention. However, the review is not limited to experimental studies.

Types of studies to be included

We will include primary empirical studies of any methodology that investigate storytelling as an intervention for people after TBI as defined above. We will exclude literature reviews or syntheses of studies, except where the primary studies are not available for inclusion. We will exclude non-empirical articles and reports such as editorials and expert opinion.

We will include peer reviewed articles, theses and dissertations.

Study identification and selection

Search methods for identification of studies

We will identify relevant studies by searching

- MEDLINE (OvidSP)
- PsychINFO (OvidSP)
- AMED (OvidSP)
- CINAHL (EBSCOhost)
- Proquest Dissertations and Theses global.
- OpenDissertations (EBSCO)
- SocINDEX with full text (EBSCO)
- Informit Indigenous
- Web of Science
- Australia New Zealand Reference Centre (EBSCO)

We will search all databases from 1990 to 27 January 2021. We will include only studies reported in English. We will seek full reports of any potentially eligible studies that are published as abstracts or conference proceedings only.

Selection of studies

Two review authors will independently consider the title and abstracts from the identified studies and apply the inclusion criteria described above. Disagreement or uncertainty about relevance at this stage will be resolved through consideration and discussion of full study reports. Any studies that may meet inclusion criteria on title and abstract screen will be included for full text screening. The above process will be repeated for full study screening.

Quality and risk of bias assessment

We will assess study quality if there is sufficient justification to report and/or synthesize *results/findings* from original studies. Quality assessment or risk of bias assessment (as appropriate) will be applied prior to any synthesis or reporting of results from original studies.

The Cochrane Risk of Bias tool (Higgins et al., 2011) will be used to assess the risk of bias of controlled trials.

The appropriate checklist from the Critical Skills Appraisal Programme (Public Health Resource Unit, 2002) will be used to assess risk of bias for other study designs (including qualitative studies).

Data extraction

Contextual data and intervention data will be extracted for all studies and mapped. Extraction against each criterion will be done using a coding system.

Contextual data

The following contextual characteristics of included studies listed below will be recorded to put qualitative findings and thematic analysis into context.

- Full citation
- Year published
- Corresponding author
- Country (or countries) of affiliation with the authors of the review
- Theoretical/conceptual perspective of study
- Method and methodology
- Sample size
- Participant characteristics (age, gender, ethnicity, socio-economic status)

Intervention data

- Description of intervention (as reported and relevant) or note absence of information. Intervention will be documented using the standardized TIDieR checklist (Hoffmann et al., 2014), with the following additional information:
 - Description of the broader system the intervention sits within.
 - Timing of the intervention in relation to stage of recovery and other rehabilitation.
 - Other support or rehabilitation the intervention is linked into.
 - Methods of narrative creation and storytelling used (including how guided the creation is).
 - Modes of delivery of the storytelling, including what is the medium of final presentation and the audience.
 - Eligibility for the intervention – including mandated or by choice.
 - Structures and limits to accessing the intervention – e.g. referral pathways, location, etc.
 - At what point the intervention is considered completed or discontinuation is determined.
- Description of outcomes associated with intervention (if relevant), and how measured or note absence of information. Outcomes include all reported outcomes, but we will distinguish between outcomes that were anticipated and those that were not anticipated. Outcomes will include quantitative and qualitative outcomes, including experiences of the intervention reported by participants.

Study findings

Findings data will be extracted as reported by authors. This may include risk ratios (RRs), odds ratios (ORs), or mean differences (MDs), or standardized mean differences (SMDs); 95% confidence intervals (CIs), or text-based qualitative findings for qualitative studies.

Study and intervention mapping

Mapping of study types, contexts, and the components and operationalization of interventions will be done using a series of tables and diagrams. The exact presentation will be determined by the data extracted and guided by reports from other mapping reviews on similar topics.

Data synthesis

The main purpose of the review is to map the types of studies done and the interventions they describe. Reporting of study findings will depend on the types and quantity of studies. If 1) a small number of studies are found, 2) it would be valuable to describe findings as well as mapping the interventions and/or 3) the studies are diverse, the study findings will be reported in a narrative summary. If there are sufficient high-quality studies of the same methodology or compatible methodology (e.g. for qualitative synthesis), data synthesis will be considered. For

qualitative findings, thematic synthesis as described by Thomas and Harden (2008) will be used. For controlled trials, we will conduct a meta-analysis if there are studies with sufficient homogeneity.

Dissemination plans

We will publish a report on the review findings in a peer-reviewed journal. We aim to present the review findings at research meetings on rehabilitation and/or TBI.

The findings from the review will be used to inform further research, which may include further review work (e.g. systematic review on a specific question), intervention development research, pilot study or experimental study.

References

- Candlish, L. R. (2020). *Who Am I Now?: Using Storytelling to Accept and Appreciate Self-Identity after Traumatic Brain Injury* (Kindle ed.): Lethan Candlish.
- D'Cruz, K., Douglas, J., & Serry, T. (2019). Personal narrative approaches in rehabilitation following traumatic brain injury: A synthesis of qualitative research. *Neuropsychological Rehabilitation*, 29(7), 985-1004. doi:10.1080/09602011.2017.1361844
- Higgins, J. P. T., Altman, D. G., Gotzsche, P. C., JUni, P., Moher, D., Oxman, A., . . . Cochrane Statistical Methods Group. (2011). The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *Bmj*, 343(d5928), 1-9. doi:10.1136/bmj.d5928
- Hoffmann, T. C., Glasziou, P. P., Boutron, I., Milne, R., Perera, R., Moher, D., . . . Johnston, M. (2014). Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *Bmj*, 348. doi:<https://doi.org/10.1136/bmj.g1687>
- Levack, W. M. M., Kayes, N. M., & Fadyl, J. K. (2010). Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disability & Rehabilitation*, 32(12), 986-999. doi:10.3109/09638281003775394
- Menon, D. K., Schwab, K., Wright, D. W., & Maas, A. I. (2010). Position statement: definition of traumatic brain injury. *Archives of physical medicine and rehabilitation*, 91(11), 1637-1640. doi:<https://doi.org/10.1016/j.apmr.2010.05.017>
- Public Health Resource Unit. (2002). Critical Appraisal Skills Programme: Making sense of evidence. Retrieved from <http://www.phru.nhs.uk/casp/casp.htm>
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(45), 1-10. doi:10.1186/1471-2288-8-45

Appendix: Search strategies for databases

General formula

S1	"Brain injur*" OR TBI OR "head injur*" OR concuss*
S2	Database-specific subject headings related to traumatic brain injury
S3	S1 OR S2
S4	storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*"
S5	Database-specific subject headings related to storytelling
S6	S4 AND S5
S7	S3 and S6

CINAHL (EBSCO)

S1	"Brain injur*" OR TBI OR "head injur*" OR concuss*
S2	MH ("brain injuries")
S3	S1 OR S2
S4	storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*"
S5	(MH "Storytelling") OR (MH "Narratives")

S6	S4 AND S5
S7	S3 and S6

OpenDissertations (EBSCO)

S1	"Brain injur*" OR TBI OR "head injur*" OR concuss*
S2	storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*"
S3	S1 AND S2

Proquest dissertations & theses global

S1	noft("Brain injur*" OR TBI OR "head injur*" OR concuss*) AND noft(storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*")
	Limit to after 1989

AMED (Ovid)

S1	"Brain injur*" OR TBI OR "head injur*" OR concuss*
S2	brain injuries/
S3	1 OR 2
S4	storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*"

S5

3 AND 4

PsycInfo (Ovid)

S1	"Brain injur*" OR TBI OR "head injur*" OR concuss*
S2	exp Traumatic brain injury/
S3	1 OR 2
S4	storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*"
S5	Exp Storytelling/
S6	4 OR 5
S7	3 AND 6

Medline (Ovid)

S1	brain N1 injur* OR TBI OR head N1 injur* OR concuss*
S2	Brain injuries, Traumatic/
S3	S1 OR S2
S4	storytell* OR autobiography OR personal N1 narrative OR narrative N1 therapy OR self-express* OR self N1 express* OR artistic N1 express*
S5	S3 AND S4

SocINDEX with full text (EBSCO)

S1	"Brain injur*" OR TBI OR "head injur*" OR concuss*
S2	storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*"
S3	<u>DE "STORYTELLING" OR DE "STORYTELLING -- Social aspects" OR DE "ORAL tradition" OR DE "NARRATIVE paradigm theory"</u>
S4	S2 OR S3
S5	S1 AND S4

Informit Indigenous (screen in database)

S1	("Brain injur*" OR TBI OR "head injur*" OR concuss*) AND (storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*")
	Limit 1990 to 29 January 2021

Web of Science

S1	("Brain injur*" OR TBI OR "head injur*" OR concuss*) AND (storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*")
	Limit 1990 to 27 January 2021

Australia New Zealand Reference Centre (EBSCO)

S1	("Brain injur*" OR TBI OR "head injur*" OR concuss*) AND (storytell* OR "auto biography" OR autobiography OR "personal narrative" OR "narrative therapy" OR self-express* OR "self express*" OR "artistic express*")
	Limit 1990 to 27 January 2021
