

ORIGINAL ARTICLE

The Potential of a Narrative and Creative Arts Approach to Enhance Transition Outcomes for Indigenous Australians Following Traumatic Brain Injury

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Abstract

Background: Increasingly, narrative and creative arts approaches are being used to enhance recovery after traumatic brain injury (TBI). Narrative and arts-based approaches congruent with Indigenous storytelling may therefore provide benefit during the transition from hospital to home for some Indigenous TBI patients. This qualitative study explored the use and impact of this approach as part of a larger, longitudinal study of TBI transition with Indigenous Australians.

Method: A combined narrative and arts-based approach was used with one Indigenous Australian artist to describe his transition experiences following TBI. Together with the researchers and filmmaking team, the artist was involved in aspects of the process. The artist contributed two paintings, detailing the story of his life and TBI. Based on the artworks, a film was co-created. Following the viewing of the film, impacts of the narrative and arts-based process were examined through semi-structured interviews with the artist, a service provider and a family member. Multiple sources of data were used in the final thematic analysis including transcripts of the interviews and filming, paintings (including storylines) and researcher notes.

Results: Positive impacts from the process for the artist included positive challenge; healing and identity; understanding TBI and raising awareness.

Discussion: This approach may enable the individual to take ownership over their transition story and to make sense of their life following TBI at a critical point in their recovery. A combined narrative and arts-based approach has potential as a culturally responsive rehabilitation tool for use with Indigenous Australians during the transition period following TBI.

Keywords: Traumatic brain injury; Aboriginal and Torres Strait Islander health; narrative; rehabilitation; cultural safety

Background

Traumatic brain injury (TBI) rates are higher in the Indigenous Australian compared to the non-Indigenous Australian population (Jamieson, Harrison & Berry, 2008;

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Katzenellenbogen et al., 2018). Despite this, a recent review showed that Indigenous-specific TBI research is limited (Lakhani, Townsend & Bishara, 2017). Only three studies have focused on TBI in the Indigenous Australian population, describing rates of TBI in incarcerated young people (Moore et al., 2014), hospital admission rates for TBI (Katzenellenbogen et al., 2018) and our longitudinal study exploring the transition experiences of Indigenous Australians in northern Australia (Bohanna et al., 2018; Fitts et al., [Under Review](#)). Furthermore, there is a conspicuous absence of rehabilitation programs developed, implemented and evaluated for the unique experiences of Indigenous Australians with TBI.

It is well established that the transition period (defined here as the 6 months following discharge from hospital) after TBI is critical, as people adjust to new abilities, roles and relationships that may continue to change over time (Doig, Fleming & Tooth, 2001; Nalder et al., 2012; Nalder, Fleming, Cornwell, Shields & Foster, 2013). Reduced cognitive and physical function following injury may lead to loss of important life roles, routines and relationships (Levack, Kayes & Fadyl, 2010). At the deepest level, experiencing a TBI can fundamentally alter a person's sense of self and definition of who they are, which may require grieving, healing and reconstruction of identity (Levack et al., 2010). Furthermore, emotional impacts such as post-traumatic stress disorder are common and may hinder recovery (Tanev, Pentel, Kredlow & Charney, 2014). For Indigenous Australians, very little is known about the lived experience of transition, preventing the development of culturally responsive transition rehabilitation programs.

Storytelling (narrative) approaches may be particularly helpful during this time, enabling the individual to form a coherent identity and life story that integrates their past self with the changes that occurred as a result of injury (D'Cruz et al., 2019). Narrative approaches have been used in TBI rehabilitation with non-Indigenous populations. A scoping review conducted by D'Cruz and colleagues (2019) found 12 qualitative research studies using personal narrative approaches in TBI rehabilitation. While none focused on experiences of Indigenous Australians, the review found that using a personal narrative approach allowed the development of a strengths-based identity, facilitated self-expression and communication, a feeling of validation through the act of someone listening, reflecting and learning about oneself, and being productive (D'Cruz et al., 2019). In the review by D'Cruz et al. (2019), the narrative approaches used in TBI rehabilitation primarily involved written approaches, with limited use of oral and visual approaches. Song writing was used in several studies. Spoken 'story telling' approaches, though limited in number, often involved use of a facilitator. No studies used painting, drawing or other arts-based approaches, and no studies reported the use of narrative approaches with Indigenous individuals, minorities or people whose first language was not English.

Alongside the potential of narrative approaches following TBI, arts-based therapeutic approaches are increasingly recognised in the contemporary literature as enhancing healing and well-being for Indigenous Australians (Cameron, 2010; Hovane, Dalton & Smith, 2014; Rasmussen, Donoghue & Sheehan, 2018) and Aboriginal communities globally (Muirhead & de Leeuw, 2012). Recently, Rasmussen et al. (2018) showed that for incarcerated Aboriginal men at risk of self-harm or suicide, participation in an art program had a significant protective effect against suicide/self-harm risk, and this effect was cumulative with each additional day of participation in the program. In this study, participants in the program were provided with a culturally safe space to practice art, socialise and connect with elders. There was no rigidity in terms of the art approach used or the number of sessions, with participation being voluntary (Rasmussen et al., 2018). Recently, Gauld, Smith and Kendall (2018) describe a narrative approach to the process of creating films with Indigenous Australians who have experienced a brain injury, reporting qualitative benefits to the participants as well as value in the educational resources produced. Hovane et al. (2014) recommend a variety of arts-based approaches to Indigenous offender rehabilitation as being consistent with Indigenous culture and law, including painting, music, song, poetry, storytelling and narrative, talking circles, drama projects, dance and movement.

Art and narrative have been used for thousands of years by Indigenous Australians to create and transmit knowledge, respond to trauma and promote healing and well-being. Recognising this, storytelling is being used as a strengths-based approach to tackle a variety of health issues faced by Indigenous Australian communities (Armstrong, Hersh, Hayward, Fraser & Brown, 2012; Barney & Mackinlay, 2010; Geia, Hayes & Usher, 2013; Nagel & Thompson, 2007; Walker, Fredericks, Mills & Anderson, 2014). Thus, there appears to be great scope to apply both arts and narrative approaches to TBI rehabilitation for Indigenous Australians, to give greater voice to Indigenous perspectives and experiences and to incorporate approaches that respect culture and are compatible with Indigenous frameworks of knowledge generation and translation (Hovane *et al.*, 2014; Hunt, 2013; Muirhead & de Leeuw, 2012).

Aim

This paper describes an arts-based and storytelling approach used to explore the TBI transition experience of one Aboriginal Australian man (henceforth referred to as the artist). Our aim was to explore the use, impacts and potential of this approach as a rehabilitation and transition support tool.

Method

The approach described here was a component of a larger, descriptive longitudinal study (Bohanna *et al.*, 2018). The original descriptive longitudinal study sought to examine a range of quantitative and qualitative measures during the 6-month transition from hospital to home after TBI for Indigenous Australians in northern Australia (for details, see Bohanna *et al.*, 2018). Participants recruited to the larger study were aged 15–65, were Aboriginal and/or Torres Strait Islander and had been admitted to hospital with a TBI. TBI was defined by one of a loss of consciousness (any duration), post-traumatic amnesia longer than 24 h or injury to the brain verified by medical imaging. Individuals meeting the eligibility criteria who had emerged from post-traumatic amnesia were approached within 1 week of hospital discharge, with interpreter and/or cultural liaison assistance as appropriate, and invited to participate in the study (Bohanna *et al.*, 2018). Though not part of the original study design, the narrative and creative arts approach described here evolved naturally as a response to the complex and illustrative stories being told by participants about their transition experience.

The artist

One Aboriginal man, aged 54 years, chose to participate in the creative arts approach after discussion with the researcher MF. Henceforth, he will be referred to as ‘the artist’ consistent with how he described himself and to protect his identity. The artist was recruited to the study after his admission to hospital with a TBI due to a fall. A strong rapport was built with author MF. During initial conversations as part of the baseline data collection, the man reported to MF that he was an artist. MF asked the artist if he would like to create a painting telling his story of transition and he agreed.

The approach

The researcher team provided canvases, paints, brushes and other necessary supplies. Following his TBI, the artist experienced cognitive, communication and mobility difficulties. To support him through this process of completing the artwork and the film, author MF visited the artist at his home, where he completed his artwork at a desk in a small outdoor area.

To manage the artist's cognitive difficulties, the artist and MF met regularly (approximately weekly) for periods of no longer than 1 h. This was to minimise impacts to the artist (e.g. fatigue). With permission of the artist, author MF recorded conversations relating to his ideas about the painting at different stages of the process. Drawing and notes were also taken by author MF to capture the ideas and concepts he wanted to convey in his art. This information was sometimes used by MF in following visits to the artists' home to trigger his memory regarding his ideas for the artwork and written storyline. During the process, the artist reviewed photo albums and family documents and spoke with his relatives to clarify and discuss key information and events related to his family's history.

Following creation of the art, posters of the two pieces of artwork were created, and the artist and MF worked together to create the accompanying 'storylines', which explained the content and significance of the elements depicted in the artwork. These posters were later used in the recruitment to help explain the aims of the project, to spark interest and to emphasise the importance that would be placed on understanding their unique transition experience following TBI. The posters also helped to demonstrate how Indigenous perspectives were valued as part of the project. The posters were a very effective talking tool with current and potential participants, sparking engagement and free flowing discussion about the transition experience. Because of this, researchers realised the power of the artist's story and art to promote understanding and healing. At this point, the research team approached author MP, a filmmaker with extensive experience in using digital storytelling through creative media. Following these discussions, the artist was approached with the idea of him being filmed while he explained his art and transition experience following TBI. During the early conversations, the artist was shown short films from author MP's website. These example films mainly included Indigenous people who had engaged with other projects related to sensitive topics. The research team explained how the films would be used and who would likely see the films.

Over several months, the research team facilitated discussions with the artist about the story he wanted to share in the film. A service provider with whom the artist had longstanding connections supported these conversations. The research team took notes during each conversation, subsequently developing a schedule of questions. The artist provided feedback on the questions and approved the final set of questions. On-camera interviews were conducted at a location nominated by the artist. In this way, the stories were co-created by the filmmaker, the artist, the service provider and the researcher. During the editing process, the artist was asked to collate photographs to accompany the content of the film and to nominate a selection of music for the film. The service provider assisted with collecting photos from the artist's family and taking new photos with the artist for the post-injury discussion in the film. Author MP edited the films, which were then sent to the artist and the researchers for feedback. Re-edits were then made based on suggestions until the artist was satisfied with the final product. Told from the artists' own viewpoint, a key goal was to enable creation of something the artist felt he owned and would be happy showing to friends, family and other community and project stakeholders.

Data and analysis

Data used to explore the approach were drawn from the two paintings and their accompanying storylines, the film and a series of semi-structured interviews conducted with the artist, his support worker and a key family member. These interviews were conducted in the weeks following the presentation of the film to the artist, his support worker and a key family member. One interview was completed face to face, with the other two interviews completed by telephone. All interviews were audio-recorded. The interview questions were:

1. Can you tell me about how you found the process to develop the film/art?
2. Has making the art and film impacted your recovery from brain injury? If so, how?

3. Has completing the art and film changed the way you see yourself and your future following brain injury? If so, how?
4. What was it like seeing the film for the first time?
5. Why were you motivated to make the art and film?

Wording of the interview questions was adjusted for the service provider and family member.

Multiple sources of data were used in the thematic analysis, including transcripts of the interviews and filming sessions, paintings, storylines and notes taken by author MF from all conversations with the artist and his caseworker during the development of the art. Thematic analysis as described by Braun and Clarke (2006) was conducted using an interpretive framework. The process followed established steps commonly used to analyse qualitative data (Pope, Zieland & Mays, 2000). All the transcripts and other data sources were firstly read in full multiple times. This intense immersion process aided familiarisation with the content and identification of patterns within the data. The broad patterns of experience that appeared across the interviews, both in relation to the specific research interests and other unanticipated or emergent issues, were identified and labelled as themes. Material in the form of sentences and/or paragraphs was then coded manually into the themes, with multiple codes being used if the text fitted into more than one theme. Thematic analysis was then used to break down, examine and compare material within the themes (Braun & Clarke, 2006). We also spoke with the participants (artist, family member and support worker) to clarify key points and assess validity of our interpretation and ensure approval to use quotations in this case study (Thomas, 2017). Continuous discussion between the authors clarified minor points, including the meaning of quotes, and allowed for agreement on the development of the themes.

Ethics approval and consent

The project had ethical approval from the Human Research Ethics Committee of the Townsville Hospital and Health Services District (HREC/15/QTHS/220), the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC-2015-2491), James Cook University (Approval H6489) and the University of Queensland Behavioural and Social Sciences Ethical Review Committee (Approval no.2015001591). Informed, written consent was obtained for all participants in the study according to ethically approved processes. An Indigenous reference group guided the study.

Results

The artist created two paintings independently, and one film was produced. Based on the artist's storylines, the two paintings explored birth, childhood and young adulthood; cultural pride; negative impact of alcohol; TBI due to falls and fighting; cognitive impacts of TBI; family violence; self-harm; hospitalisation; healing and rebirth; spirituality and identity; thoughts about the future; hope and courage; desire to reduce alcohol use. Both artworks placed the TBI event in the context of the artist's life story, his past, present and future, and in relation to family, place and culture.

Interviews revealed three key themes: positive challenge; healing and identity; understanding TBI and raising awareness.

Positive challenge

The two paintings were the first pieces of art the artist had completed after his TBI. The process appeared to reaffirm his identity as an artist and increased his confidence in his artistic skills. As illustrated by the quotes below, the process also gave him a sense of pride:

Why did I do this story? It's because it was a challenge really. Just to find out, can I paint a story of myself? It was a challenge and hard but it's good and it kept me going, in the sense of using the nugga, brain, you know? (Artist)

He took a lot of pride in what he did because it was something that he thought he could never do, because he doesn't paint that way. So I think it gave him a lot of, oh it's hard to describe, made him feel really good about himself and showed him that he can do different stuff if he has to. (Service provider)

The artist saw the offer to participate in the creative arts component of the project as a challenge. As demonstrated by the following quote, the creation of the artwork and video provided the artist with the chance to document his life journey, to create meaning and purpose for his life, and a way to re-confirm his identity as an artist:

Maybe to show my children how much I care about them and how much I want to achieve something before I pass away. And the big one is my art. I want to be, you know, recognised I can paint. (Artist)

The process provided the artist with the confidence to communicate with others about his feelings without being under the influence of alcohol:

And I believe, you cannot talk how you feel really when you've had a few drinks. You talk gammon . . . I talk a lot of hatred when I drink. And that is where I feel that being, a head injury, it's sort of, I don't know . . . it tells me [the film] that I can talk without having a drink. (Artist)

And he'd only tell stories when he was drunk and stuff like that. He'd never say anything when he was sober. I think that's what was so touching to me, and I said it to my husband, having him sit there and talk to you for hours and hours and hours, that is something unreal for me, you know, that he can talk so much. (Family member)

Healing and identity

The viewing of the film took place at the artist's home where he invited some of his family members and his support worker to watch the video for the first time. The viewing was an emotional experience: *'so many emotions that we all felt'* (Service provider). The artist acknowledges that his sense of accomplishment and pride was coupled with mixed emotions, particularly regret for things he had done in the past:

And just doing that story, it really put a tear and made my throat dry and my eyes started to weep a little bit, you know? And the thing I felt was, 'Why did I do this to my children?' (Artist)

The film also provided a platform for the artist to acknowledge past events and the impacts of his alcohol use on his family:

For family to sit there and listen to what he says and how he feels about his life, I think that was actually a good thing for his family to hear, because they'd never heard it before,

how he hates his life and hates the fact that he started drinking and hurt his family by drinking, and stuff like that. (Service provider)

I had a tear in me eye 'cause I felt that I'd done wrong to my children 'cause my ex she said "If you don't stop drinking, we're going to separate". And I said "Yeah, yeah, yeah, whatever". And just kept on doing what I'd done. (Artist)

The family member of the artist saw the film as beneficial for the artist for self-reflection purposes in the future:

It benefits them too because they can sit back and watch and think 'Oh my god . . . that's how I was?'. When he finally does decide that he's going to give up alcohol, 'Is that the way I was?' (Family member)

The process enabled the artist to reconnect and strengthen relationships with family members. Upon completion of the art, the artist sent photos of the art to his family members. During film production, the artist spoke with family members about what he wanted to share in the film, clarifying the sequence of key family events and asked family to share photos to include in the film. After seeing the film, the artist reported that communication with family members had improved:

Now they're [sisters] saying 'I love you'. It's changed a lot. They don't say 'Yeah, okay, how are you going?'. They're saying 'how are you going [name]?' And I say 'Yeah good'. Just told them I'm losing weight. They're very happy that I'm going forward with myself. (Artist)

Understanding TBI and raising awareness

The artist developed a greater awareness of the consequences of repeated head injury during the process. As illustrated by the quotes below, the artist became more conscious of safety:

Going through this project with you guys, he's understood the impact that brain injuries can have on you. He is definitely looking out for his safety more. Like now, because his balance isn't so good with his legs and stuff, now he'll wait for me. Where before he used to just rush off and say 'I'll be right.' And I'd go 'You'll fall over'. 'I'll be alright, I'll just get up'. But now, like getting up a gutter or something I'll go and stand beside him and he puts his hand on my shoulder to steady himself while he gets up there. So he's listening to us and he's being more safety conscious so he doesn't fall and hit his head anymore. (Service provider)

The other day with the sore foot, he said to me 'I can't drink now until my foot gets better because I'll guarantee I'll fall over'. (Service provider)

The process was also as an opportunity to educate others in the community about the impacts of brain injury:

That's one positive thing he's looking at, the making of the video, is that even if it helps just one other person out there understand and learn from what he's done in his life . . . If somebody can learn from what he's done and make their lives better from not going down that same track, that would make him proud. (Service provider)

Discussion

The creative arts approach used here including digital storytelling and artwork has potential as a component of a culturally responsive TBI transitional rehabilitation program for Indigenous Australians. Approaches such as storytelling and song writing allow for a strengths-based exploration of self-concept in individuals with neurological impairments (Baker et al., 2017). These mediums can strengthen the positive aspects of the self-concept and make a difference in how people living with disability view themselves at a critical time in the rehabilitation process (Tamplin, Baker, Macdonald, Roddy & Rickard, 2015). Making art has also been shown to serve as an intrinsic motivator to encourage client participation and engagement and to enable exploration of self-identity and a focus on strengths and abilities instead of disabilities (Symons, Clark, Williams, Hansen & Orpin, 2011). Improving self-concept has also been found to correlate with significant reductions in anxiety, depression and negative affect (Baker, Rickard, Tamplin & Roddy, 2015). This is particularly important for Indigenous Australians following TBI where engagement with the health system and services can often be disempowering. For Indigenous patients from remote communities, they can also be long distances from family and country. This approach encourages choice and control and creates a sense of purpose and contribution (Perruzza & Kinsella, 2010; Reynolds & Prior, 2003). The narrative and creative mediums could be used to assist the individual experiencing the TBI and rehabilitation therapist to co-design a model of rehabilitation that addresses individual priorities, an approach that embodies the idea of listening to and working with the individual.

An arts-based and narrative approach may also engender healing and identity reconstruction, specifically to think about the incident and the context surrounding how their injury occurred, allowing processing of feelings in relation to the trauma of the event (Tamplin, 2006). This healing approach may be particularly important for Indigenous Australians experiencing TBI due to assault, a common cause of head injury for Indigenous Australians (Jamieson et al., 2008). After a TBI, individuals have an opportunity to redefine or reconstruct their view of self, according to their 'preferred view' (Eron & Lund, 1996). After trauma or disruption to the life-narrative, individuals can weave a link from past events through to the present and description of a desirable future in what Morris (2004) refers to as an alternative story of self. Storytelling through creative arts can become a catalyst or vehicle for this transformation or reconstruction of identity, making sense out of the trauma while authenticating the individual's experiences. It may also assist artists to express grief, experience joy, positive emotion, flow and spontaneity (Perruzza & Kinsella, 2010; Reynolds & Prior, 2003).

The narrative approach enables discussion between individuals experiencing TBI, their families and service providers, encouraging empowerment and post-traumatic growth (Ownsworth, 2014). The narrative approach enables opportunities for individuals experiencing TBI to express gratitude to family, friends (Tamplin, 2006), and in this study, service providers, for their support during the rehabilitation process. It provided a non-confrontational way to engage family members in the transition process, promoting honesty, reconnection and forgiveness. In the context of inter-generational trauma and high rates of interpersonal violence-related head injury in Indigenous communities (Jamieson et al., 2008), this approach may provide a space for individuals and families to work through trauma, as previously suggested in the work by Gauld et al. (2018).

As identified in other studies (Hogan, 1999; Tamplin, 2006), the narrative approach produces a range of valuable outputs and can lead to other outreach opportunities for the individual living with TBI. Digital storytelling, as used in this study, is particularly valuable in the context of Indigenous Australians. This emerging method can preserve and promote Indigenous oral wisdom, while engaging community members, developing capacities and celebrating stories, family histories and lived experiences (Cunsolo Willox, Harper, Edge, Rigolet Inuit Community Government & 'My Word': Storytelling and Digital Media Lab, 2013). The creations developed in this case study are multivalent; they are data, artwork, education resources and an embodiment

of the relationship between creators and artists. They also provide a means to intervene in a wider public discourse about Indigenous health, often defined by talking about Indigenous people with disability rather than listening to them. The use of these creations is diverse. For example, in this project, we are using the creations, with the artist's permission, in the following ways: as part of feedback workshops to complement traditional presentation of research findings; in training for occupational therapy students, as awareness raising tools for use in a range of media; as a discussion tool for use by staff with Indigenous patients and their families in hospital and rehabilitation.

The approach described involves significant practical, ethical and resource considerations that must be navigated and involve the research team and the individual living with TBI. The process relied on the strong rapport built between the researcher and the artist, can be time intensive, as well as emotionally challenging for both the researcher and the artist. The artist and the other participants in this study who participated in the creative arts component were well supported during the process through existing connections with community service providers and family members. Individuals experiencing TBI engaged in a creative arts and narrative approach may experience a range of emotions as they reflect on traumatic life events both before and after injury; thus, it is essential that individuals be connected with appropriate supports. The dissemination of the resources must also be considered as part of an ongoing negotiated process between artists and research team.

This study using a combined narrative and artistic approach was effective as a research tool, beneficial for the individuals involved during the transition period, and effective as knowledge translation. We suggest that this approach should be considered in TBI rehabilitation when working with Indigenous Australians with TBI. The approach represents a culturally responsive, strengths-based approach that privileges Indigenous stories about recovery after TBI. This approach can give voice to Indigenous experiences, enhance participation and control during transition and may be useful to encourage healing.

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Conflicts of interest. The authors have no conflicts of interest to disclose.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

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