

# Exploring the impact of sharing personal narratives of brain injury through film in Australian Indigenous communities

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## ABSTRACT

**Aims:** Culturally appropriate community education about brain injury prevention and supporting people with brain injury and their families is needed in Australian Indigenous communities. Narrative therapy offers a useful method in rehabilitation that may be particularly appropriate for Indigenous people. This paper aims to explore and describe the impact of sharing personal stories on film by Australian Indigenous families who have experienced acquired brain injury (ABI). **Methods:** Participatory Action Research approaches were used in the production of films describing personal stories of brain injury for three Australian Indigenous men and their families. Participants were involved in the conceptualization, development, filming and launch of the films in their own communities (one urban, one rural and one remote). The production of the films was followed by

individual semi-structured interviews with film participants. Thematic analysis of interview data was undertaken. **Results:** While produced as an educational digital video disc (DVD) resource for improving brain injury prevention awareness and support in Australian Indigenous communities, participants identified five themes related to the benefits and challenges of the narrative filmmaking process, namely the motivation to tell their story, the experience of making the film, the social impact and benefits, the importance of the launch and the untold stories that remain. **Conclusion:** Storytelling by Australian Indigenous families through film was perceived by individuals with ABI and their families to have important personal benefits in addition to providing a culturally relevant community education resource. A recognition of the film as merely a snapshot in time is necessary however and ongoing opportunities for storytelling should be sought. Community launches of such resources are important for supporting families affected by brain injury and increasing awareness in their communities.

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## INTRODUCTION

Acquired Brain Injury (ABI) describes all types of damage to the brain that occur after birth and typically excludes neurodegenerative disorders. Most frequently this involves stroke or traumatic brain injury. ABI is a leading cause of disability globally resulting in long-term physical, cognitive, communication, social and behavioural deficits affecting not only individuals [1–3] but also families [4, 5] and communities [6, 7]. In Australia, rates of stroke and traumatic brain injury are particularly high in Aboriginal communities with the recorded rate of ABI at least three times higher for Australian Indigenous Peoples, than for non-indigenous people [8–10]. Further to this, it is highly likely that counts of disability prevalence in Australian Indigenous populations are significantly underestimated [11].

A systematic review of 26 international studies on Indigenous people with traumatic brain injury (TBI) found research gaps around level of injury and/or treatment, neuropsychological assessment, indigenous perspectives, interventions and rehabilitation [12]. This was especially the case for Indigenous Australians as compared to other nations (e.g. New Zealand and Canada). Further, despite the increased prevalence of ABI in Indigenous communities, the uptake of rehabilitation services after injury is extremely low [13].

Poor uptake of health services more generally by Australian Indigenous peoples has long been recognized as a key health challenge heralded by basic differences in concepts of health between indigenous and non-indigenous individuals [14]. Clearly, many health services are not meeting the needs of Indigenous consumers [8, 15–17]. This occurs on a background of long term disenfranchisement of Australian Indigenous people [11] through colonisation, racism and marginalization. Indigenous people have diversity in languages and groups with different health concepts and varying trust in Western services. People are fearful of leaving families and country and travelling long distances for healthcare [8] therefore offering services away from remote communities is not the most appropriate model of service delivery for many Indigenous people.

Within the context of brain injury services, many Indigenous people do not specifically address their brain injury diagnosis as it is often merely one of a range of comorbidities [13]. Furthermore, the fact that some Indigenous people live in remote areas experiencing limited services, a lack of support, geographic isolation and significant travel distances means that accessing appropriate brain injury services is logistically more difficult [18]. In a review of brain injury services in

New South Wales, Australia, issues specific to access by Indigenous Australians included cultural issues of kinship and connection to community that impacted on acceptance of centre-based programmes requiring separation from family. Services were only engaged when trust had been established and this was difficult to develop because services were not based in many Australian Indigenous communities [19].

## Developing culturally appropriate services

Traditionally, Australia has been good at identifying problems but deficient in developing solutions in Australian Indigenous health [20]. Townsend and colleagues [11] highlight that cultural perspectives on disability, a lack of culturally sound research methods and the absence of culturally appropriate assessment contribute to invisibility of Australian Indigenous peoples in health figures and equally the absence of appropriate health solutions. Calls have been made for community controlled, culturally appropriate, self-determining health solutions based on the goals of Indigenous communities [21–23]. Culturally safe services are required [24, 25]. There is a necessity to embrace difference and accept culture while acknowledging that specific communities and individuals will differ [24, 26]. Incorporating the voice of Indigenous people in healthcare is an important link in promoting cultural safety [27] as is the incorporation of partnerships with Indigenous health workers in health promotion, education, liaison and delivery of clinical services [28].

Lakhani and colleagues [12] called for more research on brain injury within Australian Indigenous peoples to inform the evidence base. This evidence base should guide culturally safe and appropriate policy and practice related to health promotion and prevention, treatment and rehabilitation as well as raising community awareness around disability services through community education in culturally appropriate ways [18, 29].

In response to the identified need for culturally safe solutions for brain injury rehabilitation in Australian Indigenous communities, a three year Participatory Action Research (PAR) project was initially conducted by the current researchers in collaboration with two self-selected remote Australian Indigenous communities in Far North Queensland [30, 31]. Consultations occurred with key stakeholders in each community. One of the key findings of the consultations in both communities was the need for community-wide education about brain injury prevention and how to support someone with a brain injury and their family in their own community. To achieve this, a need for culturally appropriate and relevant brain injury education resources for Australian Indigenous communities was identified. The development of culturally relevant materials to support Indigenous communities is more likely to be effective when informed

by participatory action, narrative therapy and critically reflective practice. In this way, collaborative partnerships in resource development will be fostered [8, 18, 32, 33].

## The potential of narrative therapy approaches in Australian Indigenous rehabilitation

The importance of narrative therapy and research has been growing leading to a plethora of differentiated methodologies [34–36]. Core across narrative approaches is the intention to give voice to alternative stories, challenge dominant ideas and recognize strengths and capacities [32]. Narrative is both a mode of thought and a method of communication central to how humans understand themselves within a cultural world [36]. Stories bind together individual and collective memories and respect personal histories within cultural traditions. It is through narratives that people often come to terms with momentous events [37]. The translation of an emotional or traumatic event into a story or narrative is likely to have multiple physical and mental health benefits [38–43]. Therapeutic filmmaking as a form of narrative has been shown to promote positive experiences, mastery, shifts in perceptions, changed perspectives of self and interactions [44].

Australian Indigenous peoples have a rich tradition in storytelling or 'yarning' [45]. Indigenous narratives are typically oral in nature and based on personal experience or historical events [46]. It has been suggested that the narratives of Indigenous people are structurally different to narratives of non-Indigenous people in that they are not necessarily chronological, interactive or anchored in context and may be intentionally vague, repetitive and without resolution [46].

Narratives have been used previously in Indigenous communities to study issues such as smoking in pregnancy [47]. Armstrong and colleagues [13] in a study of communication disorders highlighted the importance of yarning even in the context of limited speech and language difficulties. Wain and colleagues [27] provided a methodological account of collecting narratives (yarning data collection) and developed multimedia resources in the form of an open access online website with education resources developed from such yarns. Given the cultural relevance of narratives for Indigenous communities, this method seemed the most appropriate to explore in the development of an educational resource for communities. In the final year of the three year Participatory Action Research project, a plan was made to develop a digital video disc (DVD) as a community education tool based on the narratives of Australian Indigenous families following brain injury. Whilst the principal aim of the work was to have an end product that was useful as an educational resource to Australian Indigenous communities as identified within the earlier

years of the project, an evaluative research component associated with the production of such a resource was considered integral. This paper reports on one aspect of this evaluation, exploring the benefits and challenges to the film participants of telling their stories so publicly.

## MATERIALS AND METHODS

Participatory action research (PAR) represents a best practice response to the ethical concerns of research focusing on vulnerable populations such as Indigenous people [33]. PAR has been defined as an empowering process of reflective inquiry that researchers and participants undertake collectively to understand and improve life circumstances. The PAR process is directly linked to action taking into account history, culture, and local context and social relationships [48] and involves cycles of planning, acting and reviewing. The National Health and Medical Research Council of Australia recommend that all research with Australian Indigenous communities should be participatory and focused on outcome and benefits for the community [49]. Located within the final year of a larger three year PAR project, ethical clearance for this project was given through the relevant Human Research Ethics Committee. Based on the identified need within Australian Indigenous communities for culturally relevant resources, the plan to develop a DVD film as a community education tool was made in collaboration and partnership with the communities involved in the larger project. The film would be specifically for Australian Indigenous people with brain injury, their families, their communities, and those who work with and support them. It was determined, in collaboration with project stakeholders (ie people with brain injury, families, interested community members and local health workers) that the films needed to feature families living in a range of situations across the state (urban, regional and remote), to ensure appeal to a range of audiences, and a connection with as many potential viewers as possible.

Information about the proposal to develop a DVD was disseminated through community meetings in these communities and through information distributed by the Acquired Brain Injury Outreach Service involved in the project. Following the announcement of the proposal and based on their knowledge of the project, three men with brain injury and their families self-selected (volunteered) for participation in the DVD to tell their stories of brain injury. These three families were representative of the range of locations desired for the DVD. An individual series of questions were written in consultation with each family to assist with the flow of the story while filming. Each family decided who would participate in filming and this varied, but included the person with the ABI, and various family members. Filming involved the use of conversational narratives to assist with the

story telling and depicted individuals engaging in life situations, such as scenes of family members interacting and individuals participating in leisure activities. A film crew assisted in the filming, editing and production, working with families and researchers collaboratively. Filming occurred in family’s homes and communities, over a 1–2 day period with each story of different length and content. Following filming and editing, a ‘draft’ final version was provided to each family for comment on accuracy and appropriateness, allowing families to make any necessary changes. On completion of the final DVD, participants were involved to varying degrees in a ‘launch’ of each story, at locations chosen by the families involved. Launches typically included a public screening of the story, followed by a shared meal. The launch itself was an opportunity for storytelling and healing, and provided the opportunity for extended family and friends to publicly acknowledge the ABI event, the efforts of the injured person and his family, and their community.

After the launching of each story, and the distribution of the DVD, participants were interviewed about their experiences in the making, and launching of the films, and in the telling of their stories. The three men and at least one of their family members (e.g., parent) were interviewed either by phone or in person by independent interviewers not involved in the project. An interview guide was developed for the interviews (Table 1). The semi-structured interview questions aimed to elicit information about the impact of the experience on the person with brain injury, and the impact on their family members who participated. Interviews were recorded and interview data transcribed verbatim. Interview data was entered, managed and encoded using N-Vivo 8 [QSR International] to identify common themes. The first two authors completed a first read of the data to get an overall understanding of the broad issues discussed. Line by line coding was then undertaken by each of the first two authors resulting in over 30 codes. These codes were then collapsed into semantic themes and verified within the data by the third author. The whole process occurred over 8 months, from filming, to follow-up interviews.

Table 1: Interview guide

Why did you choose to tell your story on the DVD? What was it like making the DVD? What was it like seeing the finished DVD? How has making the DVD impacted on your recovery? How has making the DVD changed the way you see yourself? What have other people said about the DVD? What did you like or dislike about the launch of the DVD? How did you feel once the filming and launch were finished? Do you think it is worthwhile for other people to be involved in telling their story in this way?
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## RESULTS

Five themes emerged from thematic analysis of the collected interview data, namely (a) the motivation to tell their story; (b) the experience of making a film; (c) social impacts and benefits; (d) the importance of the launch; and (e) untold stories.

### Motivation to tell their story

The current study found that these three families were motivated to tell their story. One family member expressed the view that Australian Indigenous People do not want to speak up, and tell their story, but she was glad to have done so to educate others. She was concerned that communities need to understand how a brain injury can occur, and the impact on the family and their involvement in the recovery process. She also stressed that the family learns as they experience the changes associated with brain injury – ‘it’s a very upsetting thing to live with’ – and she wants other families to understand how ‘we feel alone and left out here and we just don’t know how to cope’.

One man with ABI was glad he could tell his story, so that others understood what had happened to him, the effect on him, and the hard work he had to go through in his recovery. His family member valued the opportunity to tell his story, as a way to educate community members about the effects of a brain injury and the impact on the family. It was an opportunity to help people who know the family to better understand what they have had to go through. In the current study, one family member was motivated in two ways to tell her story – firstly to give hope to others, and secondly for herself, ‘to get it out’. ‘I didn’t get counselling, nothing for that, and like speaking out like that sort of helped me too....helped both of us..... and that DVD may help someone else, because there is hope’. This cathartic process was observed by the project team during the filming and launching of the individual stories. The team included clinicians (Social Work and Occupational Therapy) with many years’ experience in community based practice and family work, who were able to talk with family members about their reactions. The impact of telling their story on film for one family was significant. ‘Everyone should tell their story... we went through depression, very stressful times, but doing this... we both sort of spoke and that sort of helped me a lot too, speaking out’.

### Experience of making a film

Making a film was a significant experience for participants that created mixed emotions. The importance of having and being involved in the production of such a resource was personally relevant and outweighed the emotional effect of making the film for one family member. ‘I had to relive the tragic incident...it was hard

for me...but I think we've come through it really well...the DVD says it all'. She felt that the story reflected how far the family had come, with the support of extended family and others, and they are proud of what has been achieved.

The opportunity to share their narrative in a public forum was a unique experience for all participants. 'That was something good to do, something different for me to do...I'm not that type of person that would normally do something like that'. For one family, the experience was very emotional, speaking about the event for the first time in many years. This family also expressed a feeling of pride in what they had achieved together since the time of injury. Collectively, these findings suggest that participants were proud of the film and the role that they played in bringing the project to fruition. 'He enjoyed it... that he was making it for other families to understand exactly what he is going through, he was happy'.

### **Social impact/benefits**

While the motivation to tell their story and the experience of the film were intensely personal influences of producing a film narrative, a number of social impacts and benefits were identified by participants. For the extended family unit, the process of making a film and telling their story allowed one family to reminisce about their journey together from time of injury. It provided an opportunity for the injured person to hear feedback from family on his past achievements and progress, a positive experience for him. Making the film gave one family an opportunity to talk about what the family went through with the person who was injured. This led to an increased understanding within the family. 'It was emotional for me and making it... both of us... helped us both, you know to bring everything out, what we had, you know, what we went through'. It also gave this family hope and enjoyment in telling their story, because it helps others. The positive impact of telling his story on film is reflected in the comment by an individual with ABI – 'It made me feel...a lot better than I was before.' Having the film on DVD as a resource for the family and individual with ABI was seen as a positive, in that it captured achievements up to a certain point in time, which could then be used in the future for comparison, and reflection. '..we focused on his strengths, you know, in his recovery, ....but I think the DVD is always there for him to reflect back on'.

Increased community understanding of their situation was reported by one family member, who reported that extended family and community members could now more fully understand what the person with ABI was capable of. She also reported that the film and its launch created increased interest in how her son was coping, and more people asked about him. 'I get that all the time, you know about him and how they ask about him, so I think it was really good that it was made'. The long term benefits of this resource and the impact on community

are outlined in this quote - 'There's family, there is always family commitment, family support. We've even got community support for him, you know... if the community can get together and support each other, you can make a better community...'

### **The importance of the launch**

The importance of having a launch in a location that allowed many family and community members to attend was important. The launch was the context within which personal injury became a community issue. One family member considered the benefits that this launch would bring to the whole community, an extension of her motivation to be involved in the whole project. 'I felt like it would be an excellent idea if we did take it back to his community because, you know, living on my community, I felt that there wasn't enough education around brain injury'. This motivation also had an impact on when the launch was held – '..it needed to be ...Brain Injury Awareness Week ... because all my years living home, I've never known that stuff to be talked about'.

The launches of the stories were emotional events for the families involved, with family members and others invited to speak. The launch was also a social event, involving friends, family and community members, and people of all ages. The impact of the launch on the person with ABI was positive- '...made me feel like I was somebody special'. 'They had a lot of respect for me'. 'He was very proud of the DVD and making sure different ones got copies'.

### **Untold stories**

Despite each family being involved in decisions about content and the final editing of their stories, each family expressed some regret several months later about additional content they would have liked to include, such as the struggles and ongoing difficulties likely to be faced by the person with brain injury, as well as their family. This provided insight into the process, and the need to provide additional time post production for changes or additions. Accepting that the film is a snap-shot in time was difficult for some participants when the final resource may be viewed for many years after.

Sensitivity was needed in getting the right balance between the individual's (with ABI) story and the family's story. Whilst the families wanted to accurately report the enormous impact of the injury, all involved also wanted to focus on the achievements of the individual and family, without negatively impacting on the individual's feelings of self-worth, self-esteem, and self-image. The outcome of this was that each story is told in a relatively positive manner, with some regret voiced about minimising the enormous stress and burden that was and is experienced by family. One family member said 'When I look back at it I wished I'd answered a

couple of questions a bit different, because everybody needs to hear someone that has been through it, ...I felt straight up I didn't explain exactly how [my son] had the accident.' 'I think you could easily do an update'. '...what it is saying that we all chipped in and moved along.... but now we are at a different stage'. Some concern was expressed about the reaction and perception of others because of things unsaid. 'It could still sound like the family coped, if you didn't know us and you watched it, to me it sounds like that family really got it together and they're coping and he looks like he is doing well, but there is a lot of hidden stuff in there..'

## DISCUSSION

Collectively, the current findings suggest that Australian Indigenous families derive benefits from sharing their stories through film in an endeavor to produce a culturally relevant community resource. Families are motivated to tell their stories, benefit from the experience of making the film, identify social benefits of the film and highlight the importance of the launch as a social community event. Medved and colleagues [50] have reported that, despite the common perception that Indigenous people do not want to speak out on public health issues, many participate in research to assist others and improve awareness in their communities. In a review of personal narrative approaches in brain injury, D'Cruz and colleagues [51] found four themes that are reflective of this motivation to tell their story, namely (a) expressing and communicating to others; (b) feeling validated by the act of someone listening; (c) reflecting and learning about oneself and (d) being productive. The findings highlight the benefits of participatory action research whereby researchers, individuals and communities work side by side for the greater good [52].

Researchers have identified feelings of mastery associated with therapeutic filmmaking [44] and the current study findings support this contention. Further, previous research with young people with cancer supports the benefits of having an ongoing resource created on the basis of one's personal experiences as a 'personal legacy' [53, 54]. In using narrative video for a young man with cancer, Pereira et al. [54] similarly found that such narratives are perceived to bring people closer through shared stories. In the current study, the opportunity to develop a narrative that didn't involve direct personal interaction with the community appeared to provide participants with a non-confrontational way of showing their community what brain injury meant for them. Similarly, others have found that internet blogs as narratives are a useful way to increase connectivity without the added concern of face to face social judgment [55]. In using a narrative Photovoice intervention for people with mental illness, Mizock et al. [41] similarly found that planning a recovery narrative exhibit, much

like a launch and celebrating recovery narrative work within that launch were extremely important aspects of this type of narrative therapy.

Despite these identified benefits, participants in the current study identified that narrative through film tells a story at a snapshot in time. These findings highlight the need for ongoing opportunities for narrative expression. Indeed, narrative is an ongoing process rather than a 'finished product' and may change across time [56]. This may be particularly so for Australian Indigenous peoples whose narratives take on a different structure and focus [46].

## CONCLUSION

Storytelling on film was used in this study to create a culturally appropriate educational resource (DVD) about brain injury for Australian Indigenous communities, a need identified as part of a larger participatory action project. This approach to resource development offers significant perceived benefits to the individual with brain injury, and their families in telling their stories and sharing these stories with their communities. Some families are motivated to tell their story, and enjoyed the experience of making a film. There are identified individual, familial and community benefits of the resource as well as the participatory process involved in its production. The importance of the launch for community involvement and engagement was recognized. The benefits of this form of storytelling however need to be balanced with the recognition that film offers a snapshot of a family's journey and should be supplemented by other means through which ongoing storytelling can occur.

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### Author Contributions

Susan Gauld – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Sharon Smith – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

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### Guarantor of Submission

The corresponding author is the guarantor of submission.

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None

### Consent Statement

Written informed consent was obtained from the patient for publication of this study.

**Conflict of Interest**

The authors were all employed at the Acquired Brain Injury Outreach Service where this study was conducted at the time it was conducted.

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