

Improving community-based rehabilitation for Aboriginal and Torres Strait Islander Queenslanders with acquired brain injury: identification of key dimensions to enhance service suitability

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Introduction

A two year study, funded through the Community Rehabilitation Workforce Project (CRWP), Queensland Health, has been conducted in collaboration with two Aboriginal communities in Cape York, far north Queensland, Australia, to explore issues and appropriate community based rehabilitation interventions around Acquired Brain Injury (ABI). The project developed from a recorded underutilisation by Aboriginal and Torres Strait Islander Queenslanders of formal health services, particularly those provided by the Acquired Brain Injury Outreach Service (ABIOS), a Queensland state wide community-based rehabilitation service for adults who have an Acquired Brain Injury (ABI), and is an attempt to address this inequity.

Acquired Brain Injury (ABI) has been defined as 'any damage to the brain that has occurred after birth', which can affect cognitive, physical, emotional and independent functioning. Common causes include accidents, stroke, lack of oxygen, degenerative neurological disease (1), and assaults. Brain injury imposes a substantial burden of care on individuals, families and communities, and is a leading cause of disability globally (2).

Poor health and disability indicators in Aboriginal and Torres Strait Islander populations have been well documented, including a reduced life expectancy of 15–20 years when compared with non-Aboriginal people (3). Injury rates in Aboriginal and Torres Strait Islander populations (deaths, hospitalisation, and emergency treatment) are 3 to 6 times those of non-Aboriginal Australians (4). The incidence of Traumatic Brain Injury (TBI) among Aboriginal people has been reported at 2.3%, compared to 0.7% in non-Aboriginal populations (5). Organic Brain Impairment, for example, has been reported at 7 times the prevalence in the Aboriginal population, than among non-Aboriginal people (6). Indigenous people, particularly Indigenous women, are disproportionately represented in hospitalisations for head injury due to assaults, with the head injury rate due to assault amongst Indigenous people 21 times higher than that for non-indigenous people (2).

Consulting communities

The outcomes of this two year study are a result of consultation with communities, including key health and disability stakeholders, service providers, individuals with brain injury, their families, and interested community members. The process of consultation was inherent to the research methodology, Participatory Action Research (PAR), assisted by the employment of a local worker in each community, which enabled the development of close working relationships within each community. Each of these factors will be explored in more depth.

Methodology

A Participatory Action Research (PAR) model was used to explore how ABI and the resultant disability is perceived by members of two Aboriginal and/or Torres Strait Islander communities, and what are the ongoing needs and supports of people with ABI and their families in these communities. This methodology was chosen as a means of maximising community consultation, engagement and consequently outcomes of the project for each community.

Participatory research approaches have been advocated to most accurately reflect the experiences of marginalised, rural and remote, and Aboriginal communities (7). There is a need to involve rural consumers in the planning and development of services for people with disabilities (8). Participatory Action Research (PAR) is '*an approach to social investigation, an educational process, and a way to take action to address a problem*' (9).

The essential elements of PAR are collaboration, participation, and reflection, which take place during multiple cycles of PLANNING, ACTING and REVIEW (10).

- PLANNING—extensive formal and documented discussion regarding perceived problem/s and necessary actions—individual interviews, small groups, focus groups
- ACTING—participants and researchers implement action/s
- REVIEW—of collected information, and assessment of action/s

Implementation of this methodology and engaging with communities was facilitated by an Expert Advisory Group, made up of representatives from Aboriginal and Torres Strait Islander health, the disability sector, family member, research and academic sector. This group facilitated our contact with communities across the state, inviting participation in the project.

Initially, the research plan proposed that the two communities involved would be one urban or regional and one rural or remote. However, the chosen methodology meant that communities would self select, based on brain injury being seen as a priority by at least some community members.

Two remote communities indicated an interest in this project, resulting in initial visits to these communities to discuss the project in more depth, including methodology and ethics. Both communities agreed to proceed, and the project commenced with consultation with community members, through individual and group interviews, focus groups, and informal discussion. Consultations were based on questions around perception of brain injury, the needs of someone with a brain injury and their families, supports available and those currently used, as well as barriers to support. From these consultations, planning for the research action could begin.

The methodology allowed for a flexible approach in consultation, and in the development of plans and activities. One community responded well to organised community meetings and information sessions, where few people in the other community attended these types of meetings, and individual or small group consultations proved more successful. The process of regularly reviewing actions and planning for future actions occurred through verbal feedback, often following presentation of a new development or plan. For example, the presentation to a group meeting of locally produced posters about brain injury, with a message about prevention written in the local language, provided opportunity for individual and group feedback, and modifications to wording made. These discussions with community members and key stakeholders and gaining agreement to proceed with new suggestions for action meant that the project evolved over time, directed by each community.

The PAR process also determined who within communities became involved. Key stakeholders identified themselves within the PAR process of planning, actioning and reviewing. The selection of the local worker (Associate Researcher) was an outcome of this consultation process.

Employment of local worker (associate researcher)

The employment of a local brain injury worker in each community is well supported by culturally safe health practices, similar to the use of Aboriginal Health Workers. “First level contact with Aboriginal Health Workers gives Indigenous people some cultural safety and they usually feel more comfortable relating to another Indigenous person...Cultural safety...refers to an environment where clients, families and community members have health care choices and their values and attitudes respected” (11).

A critical element of the project was the employment of a local person in each community to assist with contacts, advising on cultural and community protocols, organisation of interviews/meetings, gathering and reviewing of information as well as taking a lead role in assisting in consultations with members of the communities and actioning the plans made by the communities. The local worker provided a key to successful community engagement and consultation and was evidence of a commitment to this process.

I don't think that your program could really survive unless you have got somebody in the community who is the person for acquired brain injury. I think you really need that role. SP1, Community B, May 2008.

Employment of a local worker in each community was achieved relatively early in the project, and with relative ease, despite community concerns about suitability of local people to do the job required by the project. However, due to the PAR process, flexibility around the role of this worker, support for that person and the willingness of each community to engage with the project, one person from each community came forward and took on this position. These workers displayed genuine enthusiasm for the issue of brain injury and were willing to work closely with all involved in the project to promote activities within each community. Both workers were proactive in suggesting activities that might address community education about brain injury in their community.

I think one of the driving forces in any project is you need to make sure that you have got the project beneficiaries on side and to that extent, you also need to make sure that you have got a local person who becomes a reference point, who becomes an opinion leader. Having a local person who stays there as an opinion leader, as a reference person, gives you a bit more advantage because you can sell the product more easily. He can talk to the people after you've gone; he can talk to them in his own language and that makes it much easier for people to begin to accept the project. He has been a good ambassador for your project here. SP6, Community A, June 2008.

The PAR model meant that initially the job description for the local workers was also partly undetermined until further consultation and planning could occur. Their role was initially around assisting the Principal Researchers in consulting with the community and engaging in education and consultation sessions within the community. Consequently, the roles of the local workers evolved over time, with some differences between the two communities emerging due to the PAR process and the community consultations. In one community the focus became education of the whole community about brain injury prevention and how to assist someone who has a brain injury. In the other community, individuals with brain injury were referred for support, with the local worker having more of a role in this support work.

Final consultations in one community revealed some difficulties for a sole worker and the support available to them in their role. Suggestions to address this isolation and lack of support have included a mentoring system, which was briefly trialled in one community. This area of support for the local worker and sustainability of the project outcomes is the focus of new research currently under way.

Consulting with key stakeholders

Health Action Teams

In one community, the Health Action Team was one of the initial points of contact regarding participating in the project, and they remained a key supporter of the project throughout. Their support assisted in identifying a worker for the project, making strong links and encouraging consultation within the community, and with achieving the outcomes of the project.

In the other community, the Health Action Team was reformed several months into the project. The project team was invited to address this meeting to provide information on the project and its activities, and support for the project was given. The local workers in both communities became members of their Health Action Team, assisting to keep the project and brain injury on the health agenda.

I'm the chief of the Health Team and if you want a bit of support, just come and see us and we'll support you. If you want to have a meeting, just come and see us and we'll have a meeting you know. You come here and we'll support you, that's what we're here for. SP 5, Community B, May 2008.

Other community stakeholders

The PAR methodology requires ongoing consultation within communities, and key community groups, services and individuals were regularly consulted. These included Justice Groups, Home and Community Care Services, Primary Health Clinics, Disability Services Queensland, and other visiting services (e.g. Royal Flying Doctors Services and Far North Queensland Division of Rural General Practice), as well as individual people with brain injury, their families and other community members who regularly attended meetings or made themselves available to the project staff for consultation and review of plans and actions.

Consultations were facilitated by the use Brain Injury information sessions, using slides, DVDs, and other visual materials. Using resources from other areas, such as Victoria, stimulated discussion about the need for locally relevant and locally made resources. Other activities also provided opportunity for consultation, such as a community art day.

Specific challenges in consulting communities

1 Methodology

While the Participatory Action Research (PAR) model used in this research was critical to the outcomes achieved by both communities, it did pose problems in explaining the project to community members. Understandably, most people wanted to understand what the project outcomes would be, before agreeing to participate.

2 Culture and language

Cultural and language differences were highlighted particularly through the provision of information about the project and brain injury. Adapting content so that it meaningfully reflected the culture and context of life in these two communities was necessary for successful transfer of knowledge. The need to balance medical and professional terms with the varying literacy and educational levels of people within communities and of the Associate Researchers required careful consideration. The commitment of the local workers and other community members to the learning process and their willingness to share their own experiences provided a rich learning environment.

3 Developing trust

The Principal Researchers were both aware that time would be needed to develop working relationships with individuals within each community, and that consistency of workers, a commitment to follow through on decisions made, and employment of a local person were some of the key elements to this. It was imperative to stay focused on the methodology employed by this research, PAR, and to allow the process to develop in a timely fashion.

You've come in here, you've accepted the community and that has helped them accept you. And you have formed good relationships and I am very, very happy with what's happened here...in two years you have made great achievements....it normally takes that time just to get something up and running. SP2, WW, June, 2008.

4 Broader approach to brain injury

Experience in working in other Aboriginal and Torres Strait Islander communities has highlighted the importance of employing a more encompassing approach when consulting about health and disability issues. While ABIOS provides services to adults who have acquired a brain injury as an adult, their families and service providers, it was imperative to take a much broader and more inclusive approach to brain injury in Indigenous communities. Therefore consultation needed to be more inclusive of brain injury across the entire age range as well as incorporating causes of brain injury that ABIOS would not address in mainstream work. For example, in response to community consultations, Foetal Alcohol Spectrum Disorder and dementia were two areas that were raised in consultations with the two communities and therefore needed to be included in the consultations on brain injury.

5 Non-disclosure of brain injury

While the project's aims included consultation with people with brain injury and their families, this proved challenging in both communities for a number of reasons. Firstly, people often did not want to identify that they had a brain injury, as they felt they were getting on with their lives, and had recovered from their injury. In addition, it appeared from stories told to the project team, that many cases of brain injury had not been formally diagnosed. People were also reluctant to tell their personal stories to people who were outsiders to the community. Consultation began with those within communities who were willing to participate, and further consultations were possible over time, as people developed trust and became more aware of the project.

Consultations with service providers did make us aware of differences in opinion regarding the project from this group. One service provider expressed concern that a distinct group of people would be created by the project without offering a benefit to them, while another service provider was interested in the project identifying the numbers of people with brain injury in the community. However, this was balanced by community members reporting on the benefits to the whole community of increased brain injury knowledge. It was critical not to be swayed by individual aims or needs but to listen to the community, reflect with the community and be guided by the community. This was critical to the building of trust and relationships with community members.

It's very important, like, it's not so much pointing out well, this one and this one and this one has got a brain injury—to me it's about everyone having the benefit of the information of what a brain injury means so that when an incident comes up and there is a need, people are recognising it and knowing how they can seek help... SP 3, Community A, May 07.

6 Lack of awareness and knowledge of ABI in communities and in health and disability services

Initial consultations revealed that there was a misunderstanding of brain injury, often confusing this with Mental Health problems. Therefore, the initial approach to communities and services needed to provide sufficient information so that they could identify brain injury as distinct from other disabilities. The community education requested by the communities continued to address this issue so that people's understanding of brain injury expanded.

I've seen the community's awareness increase greatly about brain injury. I have seen people on our community being more tolerant with people who have brain injury, as a result of the education sessions. It's something now that's talked about and that's out on the community, whereas before it was probably something we didn't talk about. SP2, Community A, June 2008.

This learning has been further enhanced by local people voluntarily sharing their individual stories of brain injury during community meetings or education sessions and is indicative of community engagement and valuing of local knowledge and experience.

It's not something that's ever been explored before. There's probably never been that sort of assessment done... we've all seen knock off and we've got people in our family who have comprehension problems too. SP 1, Community B, May 2007.

7 Ongoing pressures placed on local services by visiting services

Local services, particularly Primary Health Clinics, frequently talked of the pressure of visiting services. Many local stakeholders felt the pressure of meetings called by visiting services. This project did not work from any one service base but engaged and consulted with many of them about the project. While meetings worked in one community, the other community preferred individual or service consultations and meetings. It was necessary to approach the two communities in the way that lessened the burden on them and value added to their service.

8 Competing demands within communities

Interest levels of members in each community fluctuated over the life of the project and were dependent on other events occurring in the community or within families at any given time. Open communication with key stakeholders and the local workers in each community provided information on timing of visits for maximum benefit to the community and generally allowed plans to change accordingly.

Flexibility, open communication and awareness of other people's commitments (personal and community), are critical for successful consultation with communities despite the frustration given the financial, time and practical aspects of travelling to remote communities.

Sensitivity to these competing demands and to people's ability to attend to project priorities must take a longer term view so that relationships are strengthened, allowing for longer term outcomes to occur.

when you walk around with local people in this community like Jasmine or one of our Health Action Team you know and have conversations...yarn gets around and people say those two people with Jasmine oh they're from the brain injury unit and people get to know. It's only a small community....We don't usually have people

come in and give training they usually come in for one day and it's not good enough. SP5, Community B, May, 2008.

9 Geographic remoteness, time and funding

The remote location of each community created a physical barrier due to complications and length of travel, cost of travel and visits, and contact difficulties by phone. Changes to plans were time consuming and often complicated to reschedule.

Likewise, communication, particularly with the local workers, was at times a barrier to the project. Phone contact was irregular, often relying on the use of another person's phone. Attempts to address the difficulties of communication with the local workers by setting up regular times for communication were unsuccessful. Similarly, use of other means of communication, e.g. email, was not consistently successful.

Consultation outcomes

Consultations within each community clearly indicated that each community wanted more information and education about brain injury in 2 areas:

- prevention of brain injury
- how to support those community members who have a brain injury.

Both communities wanted as many community members as possible to have access to this information, across all age ranges. It was therefore important that information be provided in the most accessible way, through various methods. Both communities wanted local resources that would more meaningfully inform community members, and actions were undertaken by the communities to develop some local brain injury resources. Project activities included:

- community information sessions and BBQ, using slides, DVDs, quizzes, and stories from community members
- training with HACC and Clinic staff
- school visits and talks, and activities with children after school
- radio interviews
- community art day to paint artwork for local posters
- filming of local DVD, and making this available on Health Clinic HitNet.

One community clearly wanted the above information so that they could better support their own community members. The other community, which is more geographically isolated, was also interested in obtaining information about linking into the brain injury rehabilitation continuum. Referrals of individuals with ABI from this community were made to the project team via the Primary Health Clinic and have resulted in positive outcomes for these individuals and their families. A videoconference with the local PHC, the person with brain injury and their family and a specialist hospital based rehabilitation service in Brisbane enhanced local service delivery, and further integrated the project work into community supports and services.

Conclusion and recommendations

The Participatory Action Research methodology was chosen as a means of maximising community consultation, engagement and consequently outcomes of this two year project for each project community. Whilst there are some obvious challenges in the consultation process, the project was successful in moving from consultations to actions to review of these actions. Employment of a local worker as Associate Researcher was imperative in facilitating this process, and therefore in achieving project outcomes.

The main need identified through this project was for education about brain injury, about rehabilitation and services and supports. The project team recommends that there is a need for locally initiated and developed resources that are appropriate to individual communities. The process of resource development provides a forum for education, as well as the end product.

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Presenters

Susan Gauld has worked as a rehabilitation coordinator with the Acquired Brain Injury Outreach Service (ABIOS) for 11 years, and has had extensive experience in community-based practice as an occupational therapist in prior positions. She is a co-principal investigator in a participatory action research project in two Aboriginal communities, researching brain injury related issues, which commenced in 2006. This research emerged from a service review and examination of referral statistics, and followed on from her involvement with another Aboriginal community in south-east Queensland, and postgraduate study in the area.

Sharon Smith has worked at Acquired Brain Injury Outreach Service (ABIOS) for 11 years as a rehabilitation coordinator. Sharon has worked as a social worker in health and disability community-based services, prior to her current position. She has researched in the area of brain injury and Aboriginal and Torres Strait Islander communities for the last two years and prior to this has been a key ABIOS worker in another Aboriginal community. As well as her interest in Indigenous issues, Sharon has focused on family issues in her work in ABIOS, being involved in research around support and education for children where a relative has a brain injury and in parenting for people with a brain injury.