

Background into Brain Injury

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1 in 45 people in society are known to have brain injury.

This is believed to be just the tip of the iceberg.

Aim of 'Background into Brain Injury'

To provide a background about the issues that may be affecting their clients with brain injury.

Christine Durham PhD, (RMIT University Melbourne); MEd: Grad Dip Ed (Curriculum); B.Ed (The University of Melbourne), an educator by training, was teaching at a private girl's school when a serious car accident after school resulted in extensive breaks to her ribs and other physical injuries and brain injury. As she could no longer remember her own name or where she lived and had difficulty speaking, eating, thinking and walking she was petrified that she had 'gone mad'. No one explained brain injury in a way that she could understand. Indeed one psychiatrist she saw wanted to commit her to a mental institution on the spot.

Since the accident she has been committed to raising awareness and translating the challenges of brain injury so that people with brain injury can understand, gain insight and feel empowered to find ways to help themselves feel and fare better. She states that education, encouragement and empathy are the keys. Now, over two decades later she still experiences double vision, balance and memory difficulties and pain, but she has written three books about Brain Injury: *Unlocking my Brain through the labyrinth of acquired brain injury* (Ventura Publishing, 2014) and *Doing Up Buttons* (Penguin Books 1997), *Insight into Brain Injury* (Springer Nature 2017), and completed a talk for *Henry Stewart Talks* (UK), The Biomedical & Life Sciences Collection - approved for USA ACCME Continuing Medical Education and UK Faculty of Pharmaceutical Medicine Continuing Professional Development accreditation (2014, 2016). These works have had a profound effect not only on those who share her experience, but also on health professionals. At the age of 67 Durham completed a PhD in Health Sciences.

Durham speaks to a wide variety of audiences in Australia and overseas, leading community and leadership organizations, rehabilitation and, health professionals, brain injury support groups, universities, school principals and parents. Her articles have appeared in magazines and newspapers and she has written widely for brain injury support magazines nationally and internationally.

From her contact with hundreds of people with brain injury and her research, Durham asserts that the plasticity of the mind, plus the plasticity of the human spirit, together boost the plasticity of human potential.

Durham writes

Many times each and every day I had proof that I was a disgusting, dumb, bumbling idiot. As my court case approached I was obliged to be assessed by many doctors. One specific day was further proof that I was stupid. I had to see two doctors - a psychologist and an ortho-

paedic surgeon. I was shaking when I emerged from the terrifying hour-long taxi ride to the first medical appointment. The doctor asked me to remove my clothes. Warning bells were sounding in my head - I did not think psychologists would ask me to take off my clothes but I had no ability to ask why, but obediently did so. It was excruciating trying to answer each question as to how the question referred to my mental state. As I eventually donned my clothes and left his office I remarked "You seem to know a lot about bones for a psychologist." After another game of playing Russian Roulette (being a taxi) I eventually found my way to the second doctor who shook my hand saying, "I'm Dr. X, I'm a psychologist..."

Needless to say, I had tremendous difficulty concentrating and answering his questions because my thoughts were swirling around "You stupid, brainless woman, why didn't you guess the last doctor was the orthopaedic one!"

Introduction to Brain Injury

Brain injury is a big problem worldwide. Each year more than 3 million people are killed, 8000 a day. Brain injury kills more people under 40 than all diseases combined and costs the US 25 billion a year on healthcare and lost productivity. It's the single greatest cause of permanent acquired disability in society. Brain injury shatters bodies, brains, spirits, lives, dreams and hopes. With loss of memory and understanding, they're bewildered, humiliated, frustrated, in denial, unable to trust themselves, other people or the world around them.

There's no medical cure for brain injury. Rehabilitation focuses on testing and remediation of impairments. Active participation of the person with brain injury requires the person to be aware of their difficulties and deficits - but studies show that when people with brain injury become aware of difficulties, they become depressed [1-8].

Testing is not the answer because they are compelled to complete a plethora of tests. Tests show our failures, and we all hate failure.

As an answer to this problem, Durham used educational principles to develop a metaphor of brain injury and a learning tool, for her PhD study. 'Keys to the Brain Injury Cage' assisted people with brain injury gain insight into their difficulties in a positive way. Using 'talk-about cards', 36 participants with brain injury talked about how the 'new me' is different to the 'old me', and the difficulties they experience. These are the things that put us in the Brain Injury Cage. How we feel about these things - sad, mad and bad locks us in.

Analysis of findings from this study showed that people were afraid, ashamed and isolated, but the good news was that they identified many keys that could unlock the 'Brain Injury Cage'. These included hope, love, learning to understanding brain injury and working things out, learning to face the facts (acceptance) and making progress. Being treated with empathy and understanding by professionals played an important role in each of these 'Keys'.

'Keys to the Brain Injury Cage' was a valuable learning and interview tool, engaging and empowering people to gain insight and understanding. It helped people to identify ways they could help themselves to feel and fare better. Keys to the brain Injury Cage brought HOPE - it helped other possibilities emerge.

Introduction to 'Keys to the ABI Cage' study

After writing a book about the personal footprint of brain injury and speaking to hundreds of brain injury support groups and professionals, Durham embarked on a PhD to study the first-person views of people with acquired brain injuries (ABI) this included 36 people with traumatic brain injury (TBI), 5 people who supported and cared for people with ABI and 5 professionals. The research revealed how people with ABI seek to make meaning and learn to fare better when re-engaging in their everyday lives. This study aimed to find positive ways that could influence professional practice and improve lives.

In the search for an engaging, original, non-medical, non-threatening way to connect and communicate with people with ABI, Durham was drawn to the metaphor of how brain injury 'imprisons the individual' and symbols that could be used to help participants with memory, cognitive and physical difficulties focus on their experience in a completely different way.

Durham had two baby fantail doves which sat on her lap or shoulder and kept her company whilst she worked on the manuscript of 'Doing Up Buttons'. Fantail doves aren't like 'proper' birds, as they can neither fly nor walk properly. As she could neither walk nor talk 'properly' she felt she was not a 'proper' person. She thought when she could do up her buttons she might be a 'proper' person.

Once Penguin Australia published the book Durham would use the doves in the fancy cage as prompts when she had media interviews, or when speaking to groups to remind her to explain how fantail doves are bred to be like this, so when they are released, they cause a commotion, and flutter in the air, providing a guide to help the homing pigeons find their way home. This prompted her to say that she hoped 'Doing Up Buttons' could cause a flutter to help people with brain injury find peace and hope.

Over the years she'd often look at the cage and think that brain injury is just like being locked in a cage and the key is thrown away. This was how she developed the metaphor/learning tool using the cage, her old walking stick and a wooden pole topped by a wooden flying pig with fly-wire wings, as an interesting structure to hold 'talk-about' cards. The cards contained information people with ABI had talked to Durham about, and the statements were used to invite participants to talk about their experiences.

Thus, symbols and words were combined to assist people reflect on their experience of ABI. The participant guided interview was a conversation with a purpose - to help participants express their own experience of ABI and review things that helped them in a positive way. This metaphor-model was called 'Keys to the ABI Cage' to give the process a positive focus.

The cage itself is 80 centimetres high and 160 centimetres high when the pole of the flying pig is added. It is 100 centimetres wide with the walking stick inserted. This object, the cage itself, was physically transported to many interviews. It immediately captured the interest of the involved parties and the simplification of the complicated issues of brain injury allowed participants to reflect and more easily understand how ABI affected their life.



Figure: Keys to the ABI Cage.

For orthopaedic professionals, the study findings about factors negatively effecting clients could provide a relevant background to treating people with brain injury.

However, a brief overview of participants, method and data analysis now follows. Full detail about the study can be found in 'Insight Into Brain Injury' (Springer Nature 2018).

Participants

Obtaining participants for this study differed from many studies into people with brain injury which draw upon clients from specific hospitals or rehabilitation facilities. Thirty-six people with brain injury, and five professionals and five people who care for and support people with brain injury were selected from people volunteering to participate after reading about the project in brain injury support organizations. Thus, participants were from a wide geographic area. As the main aim of the study was to do no harm ethical considerations informed the inclusion criteria: they should not be in a fragile state, stressed or amid a crisis or waiting a court case, and be between the ages of 19 and 60 years and at least two years post injury. Professionals working with people with brain injury, and mothers and wives of people with brain injury were also interviewed for data triangulation [9] and different methods for methodological triangulation [10].

Interviews

People with brain injury were divided into three groups which commenced by first viewing a Power Point presentation describing the Cage and explaining what they would be required to do. Participants in two groups were sent a 'Reflection Kit' - a digital storage device containing the Power Point with voice over, along with 'What ABI means to me' sheets. At specific places in the presentation these participants were asked to fill in their comments on the sheets which were returned to Durham.

One of these groups also had an interview in a location of their choice - a local library or coffee shop near to their home. They were shown the Power Point again, then they were given another set of 'Talk-About' cards and asked to take each card and place it in a 'Do' or 'Don't' box and talk about the words on the card or something they reminded them of - if they wanted to.

The third group only participated in the face to face interview. All groups were given 'Some further thoughts' sheets along with organizations to contact if revisiting their experience had upset them. Durham followed up with an 'Are you ok' phone call the day following the interview or after receiving the 'What ABI means to me sheets'. A further phone call, a week after the interview was made to make sure they were ok. Participants were sent thank you cards with photos of the Cage and 'Keys' to release them from the Cage.

All participants who engaged with firstly the reflection kit and later had the interview stated they found the process helpful in giving them time to start reviewing their experience. Although the Cage and cards were bulky and presented physical difficulties 'Keys to the ABI Cage' generated interest, humour, understanding and empathy and encouraged participants to share their thoughts. As one participant said: "I've been denying I have brain injury for seven years but one hour with a bird cage has let me see for myself that I do have ABI".

Findings from this study - factors that had a negative effect on how people with brain injury feel

The 150 000 words of transcript from the interviews was analysed using interpretative phenomenological analysis (IPA) [11]. The superordinate theme that emerged from the data was that ABI damages not only the person's brain, body and beliefs, it also damages their hope, honour and trust, and their safety and security.

This superordinate theme was revealed by examining data firstly from the words in the first case, then emergent themes were identified and from them four overarching themes were recognized.

Overarching themes

Loss, lost and trapped: afraid, ashamed and isolated

- Loss of identity and the phenomena the 'old' and 'new' me and comparisons to life as it was compared with life as it is now.
- Loss of understanding
- Loss of trust: can't trust myself, other people, the experts, fate/God/luck
- Loss of faith/religion/being punished by God
- Loss of choice

Participants with ABI did not approach the process of reflecting about their experiences in a straightforward, linear way. But as they held the 'talk-about' cards, they reflected and came to realisations as they spoke. They circled and revisited ideas and came to further realisations, at times contradicting themselves.

Most of the participants told stories to illuminate the overwhelming effect of being a 'different' person. They struggled to function. They were overcome not only by physical, mental, communication and emotional difficulties and pain but they were also overpowered by a sense of loss. They were aware that they had lost the 'old self' and were struggling to live with their 'new' selves. Some participants spoke of the sadness of realising and accepting that they would never be their 'old' self again.

In their struggle to 'make sense' of themselves, most participants told stories about how they constantly compared their 'old' and 'new' self: how they thought they deserved to be treated by people including by their family, friends, health and legal professionals, and how they perceived that they were actually treated; their slow recovery progress compared to the effort they were making. Many stories demonstrated that life prior to their ABI seemed 'more fair' than their post ABI life, where they had no choice, and little power.

A plethora of overwhelming and multiple losses compounded the feeling that the 'old' self that they knew, understood, trusted and depended on, had gone. The 'new' self could not be controlled, trusted or understood. These difficulties also cut the person off from 'normal' people, isolating them, making them feel like an alien. Without a personal identity and clarity over their own self, the presentation of self becomes impossible and the self is constructed in the way others treat them. This 'looking glass self' may not be a self with which the person feels happy!

Most participants spoke about being bewildered, confused and lost because they could not make sense of, or understand what people were saying, what they should do, or how they should accomplish simple tasks. They could not understand the 'new' self, the 'stranger' who had taken over their body, brain and life. Just 'getting by' was complicated, tricky, and demanded all their attention and effort.

This 'new' self could not be depended on, for example they could do some things on one day but not the next, at one time of day but not another time. A number of participants doubted themselves and said that they felt guilty and asked Durham if she thought they were an 'imposter'; others stated they wished they were more damaged with broken limbs so people would understand they were 'injured' or 'damaged'. Participants generally were confused and frustrated with their changed lifeworld and they told stories that illustrated the stigma of ABI.

As the participants held the various 'talk-about' cards, stories emerged that clustered around trust: They could no longer trust themselves; they were aware that they did and said the 'wrong' thing, and, as a consequence had lost confidence: they were aware they could not control their tongue - they were not tactful, their decisions were not right. Many participants had a 'gut' feeling that they could not trust themselves.

Almost every participant told of experiences that proved that they could not trust other people. They tried to hide their difficulties/differences/deficits from their family, friends, the public, and medical professionals but they were 'exposed' and vulnerable. Most participants spoke of 'disappointing' encounters, when they thought people would understand/have empathy and sympathy with them for the difficulties they were experiencing. When people didn't 'understand' (and make allowances) participants became more wary of trusting others.

One third of the participants expressed disappointment with the way their family didn't 'understand, some felt 'scared' of and 'lost trust' in their families: being physically attacked ...smacked by his wife, distressed because her parents would accuse her of being lazy but that she was trying hard and suffered from 'bad fatigue'. A majority of participants had lost trust in their friends who did not 'see what was really going on', or who said they seemed to be "OK". If only he could reply "Oh yeah. Swap places with you then".

Some participants had bad experiences with professionals and a great many participants expressed distress that they did not receive 'enough' care or understanding from medical professionals. Their stories inferred that they thought professionals would be the 'one group of people who would understand them'. A large number of the participants were distressed because of the pessimistic outcomes suggested by professionals.

Religious beliefs had both a negative and positive impact upon the participant's life. Some had lost trust in God, and many were struggling to make sense of why God was punishing them, or they had queried if God had caused their ABI to teach them a lesson, or trust God to protect them in the future.

Over half the participants said that they were terrified they would have another accident (if it had happened once it could happen again), and that they wouldn't have 'the will or the energy to fight brain injury when it happens again'.

The loss of trust (in themselves, others, God and the future) negatively affected their lifeworld.

No longer like a 'normal' person

- Can't function 'normally'
- Can't understand or communicate 'normally'
- Can't control emotions 'normally'
- Weird abnormal issues

The second overarching theme clustered around losses came together around a mass of data relating to a comparison between how participants perceived what a 'normal' person did. Because they couldn't do these things they were no longer 'normal'. These differences and deficits made life difficult and also were symbols that they were not like a 'normal' person any more. None of the participants referred to themselves as 'disabled', suggesting that many people with ABI do not readily identify with being labelled 'disabled', however they told stories and compared themselves to other 'normal' people, and this comparison had a negative effect on their lifeworld.

All participants could not function 'normally' to do 'normal' things such as walking, driving, working, going out, socializing or traveling. Most participants had balance problems which they described as 'very clumsy', 'dodgy', 'fineline'. Some participants accepted their physical difficulties in a matter-of-fact way and they joked about the inability to walk 'normally' for example, or ignored that they had difficulties. Impaired vision, loss of one eye or being legally blind was accepted stoically by several of the participants.

Some participants described how in the early months after their injury, they were 'freaked out', frightened and disturbed when they lost the basic 'normal' ability to know how and when to eat, when they found themselves dribbling and choking, because their 'brain had

forgotten how to tell the throat how to swallow'. 'Normal' people can eat 'normally', they couldn't, so they felt like a freak, one participant still had to put her fingers down her throat to help herself swallow. Several participants spoke about their loss of smell and taste.

Sleeping was a problem for many participants. They had difficulty sleeping at night, or as one participant expressed it as her brain 'could no longer go to the place of sleep'. Most participants had adapted to their fatigue, they 'knew their limits' and limited their daily activities to cope with the mental, physical and emotional exhaustion and weariness. Coping with their fatigue was accepted as part of their life with ABI.

Many participants spoke of how frustrated and embarrassed they were when they couldn't understand what people were saying or could no longer read. The inability to speak so that other people could understand was very upsetting. The 'talk-about' cards were prompts to help participants with communication difficulties. Holding the card with a topic in their hands helped them to hold a conversation about how they had difficulties speaking, listening and understanding.

Many themes were not isolated units in themselves, for example the following issue could be placed under the 'communication' or 'weird' themes. Several participants discussed their puzzling inability to use the telephone, yet they did not remember this or 'have the words to ask for help' at an appropriate time. This made them doubt themselves, it was taken as proof that they were not 'normal' and made them embarrassed, ashamed and afraid they were crazy.

For many participants, a further symbol that they were not like normal people was the experience of uncontrollable crying (and laughing) in public.

It also emerged from stories from many of the participants that they were struggling with a variety of perplexing 'invisible' issues including 'left neglect', where they neglected the left side of their body. A small number of participants spoke about 'weird' metaphysical issues, where they did not know who was talking (the other person or themselves). These invisible issues had a profound effect on them. Several participants stated that their left neglect affected them as it was 'strange' and 'weird'. One participant who was legally blind, said that if she could have one wish, rather than her sight, she would want to get the sense of her left side back, so she felt 'whole'.

Distorted vision, double vision, and seeing in other peculiar ways affected some participants. If vision was 'confused' it was 'confusing' to see things that weren't there - if you couldn't believe your eyes to tell you what was real - how do you know what was real? Tunnel vision meant the person had many blind spots - and this caused frustration and walking difficulties it could mean they sensed someone was in their blind spot. These strange and 'weird' aspects of ABI affected the participants' life.

Damage from emotional fallout

- Sad: disappointed, depressed and distressed
- Mad: angry, frustrated, crazy/insane
- Bad: guilty, stupid - bloody idiot, embarrassed

The next overarching theme 'The emotional fallout' considers the emotional difficulties in greater detail as it was a category that was sufficiently large and important to stand on its own. But uncontrollable crying and laughing were the outward emotional outbursts that caused participants public embarrassment and shame, and private shame and puzzlement.

All participants identified with the 'Sad', 'Mad' and 'Bad' talk-about cards (and their subsections) that were positioned *inside* the 'ABI Cage'. These cards led them back to refer to stories they had previously told or they told new stories to illustrate their point of view. In the development of the tool it was hoped that the employment of these three small everyday words could provide a 'softly softly' approach (a non-psychological, non 'professional') way to broach profound, personal, serious matters. The participants 'got' the way the words were used, many said it was an amusing way to think about how they felt. They thought it 'was clever' the way the different meanings were unpacked. These 'talk-about' cards encouraged engagement and reflection. There was also a crushed soft drink can, a snake and a snuffed-out candle in the cage to invite reflection on how they felt about their ABI.

The crushed can was widely recognized as an example of 'myself' (a crushed human being). Some participants asked for me to open the cage door and let them hold the crushed drink can. "This is me" they said.

Most participants placed the 'Sad' talk-about card in the 'Do' box. Many participants expressed *disappointment* with themselves, their lives because they could now no longer achieve their dreams, the fact that day to day survival was difficult, that financially their future was changed for the worse, that they no longer had careers they had loved, marriages had broken down - life was no longer predictable or controllable. They were ashamed and disappointed. They talked about feeling depressed, hating themselves, having contemplated suicide or disappearing, and feeling powerless. One participant spoke about the reluctance of professionals, family and friends to discuss their suicidal feelings with them. Many participants also identified with the '*distressed*' talk-about card - that the ABI experience was distressing.

Anger was a big problem for many participants and they told stories of their terrible anger and rage, but the majority of respondents reported they had feelings of frustration, they felt annoyance with themselves rather than anger, and anger at situations they were put in because of having ABI and their loss of choice. Anger was expressed at the way the person was treated by professionals.

All participants placed the 'Frustration' talk-about card in the 'Do' box. 'mad/ frustrated - that's brain injury in a nutshell' and their stories told of the struggle of trying to cope with a brain and body that does not obey the person, when they can't understand why they behave in a certain way, when they are forced to rely on others, or to completing ordinary tasks when they are blind.

Many participants said that in the years following their accident they had believed they had gone mad or insane, that they often questioned if they were crazy, mad or nuts. One participant thought the professionals were trying to make her feel insane on purpose, or was it 'part of a stupid IQ assessment'. These participants were profoundly affected by believing they were insane.

Most participants expressed *guilt* in some story or other - either about pain they were causing their family who they felt they had 'let down', for what they had put their family through, because they had not avoided the accident, because they couldn't make themselves better, or because they had 'let' their ABI affect their life too much. Over half the participants felt guilty they had not 'tried hard enough to make themselves better'.

Many male participants expressed feeling like a 'bloody idiot' when they do or say the wrong thing, when their poor balance means they fell about when they walked - then they are accused of being drunk, stereotyped as being a loser, or get declined entry to bars. Women felt bad about other issues such as: doing and saying the wrong thing; one participant elegantly called this the 'loss of social graces'; others would query if the inappropriate action was due to their ABI or were they 'just stupid?' Not being able to complete simple tasks such as doing up their buttons resulted in them 'feeling pretty stupid actually', being embarrassed because they are 'slow and can't concentrate, or can't understand things'. The participants felt ashamed, afraid and isolated because of the emotional fallout of ABI.

The rehabilitation experience didn't suit me

- Loss of hope
- The rehab experience was disempowering

- Professionals don't know what it is like (brain injury or being in 'the system')
- Bad rehab experiences
- Not a textbook case but treated like one

This study did not set out to critique rehabilitation, there was only one talk-about card: 'Rehab'. It was up to the participant to simply place the card in a "Do" or "Don't" box or to talk about their experience. The participants were not asked to focus on expressing views on their rehabilitation experience. However, this was seen by many as a significant area that they wished to speak about. Over half the participants expressed opinions about how upsetting they had found rehabilitation experience.

Reviewing the data revealed issues around a perceived lack of understanding, power, truth, fairness, justice had profound long-term ramifications on many participants' sense of wellbeing. Some participants had forgotten what was *said* and *done* in rehabilitation, but not how rehabilitation made them *feel*. They talked about people and events they did not want to think about, but found they could not forget.

The following long quote has been included because the perception this participant had about the rehabilitation experience still upsets her years later:

"Rehab was so awful actually I don't... it's something I don't talk about, I don't think about, if I do, I cry...I've always believed it was my own fault that I didn't like rehab. In terms of that, I was in a terrible place, so it was always going to be bad... I was suffering ...anywhere would be bad... but this was worse. Cause it was bad at home, but this was really bad. And I think it's the way, it's a system that.... it's a hierarchy, it's really structured, it's really rigid, there's rules, there's no compassion, there's no understanding, it's not about the individual, it felt like you were in a factory...that you were just being pushed through, you were a number...you were just on this treadmill"

A few participants said they had been damaged twice - once by ABI, and then by rehab.

Summary

The statements made by the participants with ABI in this study, demonstrated that they had awareness and insight of things that negatively affected their life. These themes left many participants swamped by their experience.

Throughout the interviews many participants modified their statements as they reflected further about an issue. Most surprising were two participants who had stated that they had suffered from depression and been suicidal until recently but later in the interview they stated that having the opportunity to think and talk about their ABI experience with 'Keys to the ABI Cage' they now realise that ABI had been both the *best* and *worst* thing that had happened to them in their life. They had moved from feeling that life was not worthwhile to feeling that life was worthwhile, they had been enriched by their struggle. They now appreciated being alive, and they were aware of their strengths and weaknesses and they felt wise.

So, the negative themes are not the whole story - participants with ABI had also discovered 'Keys' to release themselves from the 'ABI Cage'.

The often catastrophic, always challenging and complicated nature of ABI, means a conclusion could be reached that the story of people with ABI is bleak and hopeless. However, this study showed that great challenges and satisfaction are not mutually exclusive.

This article aimed to give orthopedic professionals a background into how their client with ABI may be beset by challenges. In concluding it is important to revisit the 'Keys' identified by the participants in this study at the commencement of this article: hope, love, learning to understand ABI and working things out, learning to face the facts (acceptance) and making progress were vital 'Keys' that unlocked the 'ABI Cage'. For the person with brain injury each and every professional can help them find these 'keys' by showing empathy and un-

derstanding, explaining information in non-medical language, cease putting the two to five years recovery time limit on 'improvement', by carefully examining the reason for and benefit to every test given to people with brain injury, (and explain the findings and what the person can do to improve) and to never say "you will never..." and remember the importance of HOPE - Help Other Possibilities Emerge.

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