The Impact of Brain Injury on Relationships Across the Lifespan and Across School, Family and Work Contexts

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In this article we define the sequelea of acquired and traumatic brain injury in terms of impact on relationships, including family and social roles. The rehabilitation of children has implications for their role within the family and as pupil; and for adults, in their roles of parent and work colleague. We describe the ways in which relationships organise around the brain injury, via a system of mutual influence and feedback loops, and how the relational network may buffer the stress and strain caused by injury and illness. Further discussion of the issues as applied to couple and family therapy, group therapy, vocational rehabilitation and wider support systems are presented. While there is no one overarching theoretical framework for conceptualising the issues, social-cognitive, systems and narrative perspectives make useful contributions.

The onset of severe brain injury immediately, and often permanently, changes the life of the individual and can have a devastating effect on others around

1 Contributions to this article were generated during a meeting of the TBI families network. http://www.jiscmail.ac.uk/lists.tbifamilies.html
that person. Each individual who feels the impact may experience a range of distressing emotions, in varying degree, including isolation, abandonment and loss (Lezak, 1978), anger and guilt (Thomsen, 1974; 1984) and, most of all, a sense of fear, incompetence and lack of mastery (Hanks, Rapport, & Vangel, 2007). In general it would appear that, as with other chronic conditions such as cancer and heart disease, family and social support play a critical role in recovery after brain injury. In this paper, we present the expert opinion of six clinicians from four neuro-rehabilitation settings across the UK using case and service examples to illustrate the impact of brain injury on relationships across the lifespan and different contexts.

Illustration – Sam (aged 11)

Sam gets up late and goes into school less prepared than usual, a situation made worse because of the brain injury he sustained in a road traffic accident when he was younger. This disorganised start to the day then leads to a build up of tension which results in an outburst in school. When his parents later collect him from school he is distressed which in turn impacts upon the family dynamics that evening.

Writing from a social-cognitive perspective Anderson & Chen (2002) state that “one’s sense of self including thoughts, feelings, motives and self regulatory strategies may vary as a function of relations with significant others” (Anderson & Chen, 2002, p.620). Moreover, Taylor, Yeates, Wade, Drotar, Stancin & Burant (2001) highlight the bi-directional nature of influences on outcome for children with brain injury. A cyclical pattern was found in their study, namely that higher parent distress at six month post injury predicted more child behaviour problems at 12 months. The figure below illustrates the inter-relations of the network / systems and the continual impact of brain injury upon all aspects of the network. Systemic therapy holds that individuals often act in ways that attempt to maintain homeostasis; the principle of positive connotation that family members are always well-intentioned but constrained by their understanding (Vetere & Dallos, 2003).

Yeates (1999) has argued that an integrated multi-level model is needed to evaluate and predict outcome after brain injury which then requires multiple levels of intervention.

The impact of brain injury

Brain injury affects children in different ways and severity of injury does not always predict outcome. Middleton (2001) emphasises that there are likely to be
many children whose difficulties in later childhood are not initially linked to an earlier brain injury because significant others lack knowledge of the condition. Wade, Taylor, Yeates, Drotar, Stancin, Minich, et al. (2006) found that long term parental and family response to child brain injury worsened at four to five year follow up, particularly around approaching adolescence and young adulthood when allowance may not be made for the prior injury. Wade et al. (2006) also found higher levels of parental distress in the moderate brain injury group, than in either a control group of children with long term orthopaedic injuries or a group of children with severe brain injuries. Interpretations offered for this include the possibility that the sequelae of injury may be more unexpected in children with moderate, as compared with severe brain injury and these children may struggle to meet parental expectations. Middleton (2001) suggests that mental health services should be alert to the possibility of an earlier brain injury when children and young people present with behavioural and emotional difficulties.

Illustration revisited - moving to a new secondary school

*Sam has recently moved school and like many children after brain injury*
be tires more easily. The need to adjust to the more demanding environment with frequent changes of teachers and a personal timetable poses new challenges which impact upon his behaviour. His new teachers interpret his behaviour as attention seeking, which increases his feeling of isolation. His parents feel disappointed as they accept the school’s view of the situation. Sam internalizes this disappointment and learns he is ‘difficult’ or ‘stroppy’ when in fact he is tired and struggling to cope with change. The situation is made worse because teachers believe Sam ‘can do things when he wants to’ because in the mornings when feeling alert, he can complete an exercise, answer questions or put up with teasing in class, but not later on in the day.

**Language and communication skills**

Lees (2005) states that, “the largest group of children with acquired language problems are those who suffer brain injury of varying severity” (Lees, 2005, p.65). Among pragmatic difficulties, individuals find the organisation of discourse difficult as well as the skills of making inferences and interpreting ambiguous sentences (i.e. skills that depend on social cues), often despite apparent adequate performance on standardised language tests (Yeates, 1999).

*Illustration revisited – impact of language and communication skills on learning*

Sam’s old learning remains intact while a pattern begins to emerge of new learning being harder to absorb. The increasing demand for multi-tasking, processing written and verbal material simultaneously, that is required in secondary school adds to the problem and lowers his self esteem further. Because Sam is able to read and has good general knowledge, his teachers remain unaware of hidden difficulties – to them he is just not motivated.

**Memory and attention skills**

Episodic or narrative memory such as the recall of a sequence of subjectively experienced events may be preserved while working or prospective memory (defined as the ability to remember things for short periods of time, long enough to carry out some intended action) may be impaired, showing in both a more general difficulty in retaining instructions and specific difficulties for example, with arithmetic skills (Catroppa & Anderson, 2000). Attention problems are more likely to manifest when completing tasks which require working quickly or with tasks requiring complex processing (Anderson & Pentland, 1998). Writing can present particular difficulties as it requires the integration and synchronization of a number of processes and often also needs to be carried out at speed.
Illustration revisited – reading and writing
Sam is finding reading and writing more difficult and his speed is slower while he habitually writes less than his peers. Switching tasks adds to the strain, for example, reading from a book then from an interactive whiteboard, or moving from text to diagrams and back again to text. Teachers are unable to motivate Sam to persevere with tasks because of their non awareness of the history of brain injury. Their non awareness also means assistive resources including keyboard access or supporting software programmes will be less likely to be available. This whole experience impacts on Sam’s motivation to do homework. He becomes more and more isolated from his peers. In breaks Sam is not part of the group and then arrives late for lessons as he does not always remember where lessons are to be held. Some days he prefers not to attend at all rather than continually be late.

Self regulation and social integration
A crucial difference when dealing with children compared with adult survivors of brain injury is the impact upon the developing brain and the non appearance of expected skills in self regulation rather than their loss. The long term impact of brain injury upon self regulatory systems which becomes apparent in late childhood / early teens can be particularly disheartening. Schools may start to question what parents are doing, seeing the situation in terms of insufficient disciplining or not enough support and parents often feel at a loss to deal with yet another set of problems. The child / young person becomes frustrated, engaging in behaviours that he may be aware are not the most appropriate, but feeling at a loss to problem solve and generate alternative solutions. Ganesalingam, Yeates, Sanson, & Anderson (2007) found that children with moderate to severe brain injury were more likely to propose aggressive and avoidant solutions to social problems and less likely to generate assertive solutions. Such behaviour along with the slower speed of processing (e.g. in catching on to jokes) and less awareness of social nuance can lead to an increased risk of bullying. Middleton (2001) notes that, “loneliness and a sense of being set apart can be experienced and subsequently these children may make friends among those who are part of a group whom their parents consider unsuitable and a bad influence” (Middleton, 2001, p. 173). The student requires that those significant others outside the family including peers and school staff have familiarity with his personal history and with brain injury more generally.

The impact of adult brain injury on relationships
As when a child sustains a brain injury, when an adult sustains such an injury the family is expected to make significant adjustments in the midst of an
uncertain prognosis, often without any prior experience or frame of reference to prepare them. Social roles and family routines, such as spending quality time together in a regular and predictable manner may become difficult and family cohesion compromised by numerous hospital visits. Below we further clarify the consequences of brain injury on relationships, introducing a new case illustration and developing some of the earlier themes but applying them to an adult world.

Illustration – Bill (53 years)
Bill, a taxi-driver, was attacked with a metal bar when he confronted a group of non-paying customers. As a consequence, he suffered a severe brain injury and loss of consciousness for many days. Years later he presented to mental health services because of constant headaches and depression.

Fatigue
Physical or mental fatigue is well recognised (Ziino & Ponsford, 2005) but social fatigue less so. Feedback from clinic indicates people have a poor tolerance for noise and find simultaneous conversations with more than one person tiring. The person’s motivation to socialise may be affected, so also social identity processes (e.g. if one’s old identity was to be sociable). Visits to the family home may need to be managed in a way to be not too overwhelming, as is often the case when too many people arrive at once. If the home environment is not managed then people with brain injury can experience frustration followed possibly by withdrawal, which is very confusing and sometimes frightening for family members, particularly children.

Illustration revisited – fatigue management
Bill spends more and more time at home, usually on the sofa watching television. He is often charged with looking after the children but pays them only scant attention because he finds it tiring to be around them. His friends stay away because he tends to ignore them when they visit. He tries to keep active, even joining a gym but reports that he ‘pays for it’ the next day when he needs to rest all day. In time he learns to exercise for short durations only and pace himself.

Empathy and role relations
In the context of a couple or family relationship, increased difficulties with perspective-taking may be interpreted as reduced empathy and sensitivity (otherwise known as ‘theory of mind’ skills; Havat-Tomassin, 2006). Emotional
factors, denial or lack of insight have the potential to create a contesting dynamic at home as family members disagree over the nature of problems (Yeates, Henwood, Gracey & Evans, 2007), for example, poor initiation may be perceived as laziness when in fact, there is a neurological basis. Parents of a young adult with brain-injuries appear to adopt the nurturing and protective role more easily as for them it is only natural but for spouses it is relatively new (Gan, Campbell, Gemeinhardt, & McFadden, 2006; Kreutzer, Gervasio, & Camplair, 1994).

**Marital and sexual relations**

A number of studies have documented the high rates of family breakdown and separation following brain injury (e.g. Oddy, Humphrey, & Uttley, 1978). However the chances of success in marriage appear much higher for certain groups, particularly older couples who have been married for longer or those who suffer less severe injuries without accompanying trauma (Kreutzer, Marwitz, Hsu, Williams, & Riddick, 2007), or for those who marry post-injury (Charles, Butera-Prinzi, & Perlesz, 2007). Generally, marital relationships come under greater strain perhaps because taking on personal care tasks is incompatible with the role of sexual partner. Indeed many spouses report that when they begin to do more of these tasks, and take on the role of unpaid carer ‘a line is crossed’ (Gosling & Oddy, 1999).

**Illustration revisited – couple relations**

*Bill had been about to separate from his wife at the time of the injury because of his unsociable working hours and lack of involvement at home yet the injury has pulled them closer together. Sexual relations have been on hold for some time, for Bill because the anxiety of not performing is weighing on his mind whereas for his wife because things just don’t seem right, at least not yet.*

**Parenting issues**

Research has highlighted poor relationships between injured parents and their children, with increased acting out of emotional problems (Pessar, Coad, Linn, & Willar, 1993). Ongoing attachments to both parents and attempts to maintain a degree of ‘family homeostasis’, depending on the child’s degree of resilience, may lead them to internalise family problems and become symptomatic in some or other way. If a parent over-reacts to fairly innocuous incidents this makes matters worse and can lead to heightened sense of fear for the children (Butera-Prinzi & Perlesz, 2004).
Illustration revisited – family relations
While on the surface Bill is taking on more responsibility at home, in reality he finds it difficult being with his children for any length of time. However, he keeps a lot of these feelings to himself and has become quite uncommunicative. Over time his children feel increasingly estranged from him, as if they were ‘walking on egg-shells’.

Therapeutic Interventions

Couple and family therapy
The call for systemic therapy in response to neurological illness and injury has been made by numerous authors (Muir, Rosenthal, & Diehl, 1990; Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002; Sander, 2005), yet the detail of how this is implemented has often been omitted. In a paper about practices that hinder the adoption of a relational frame, Yeates (2007) has observed that, in particular, two features of neuroscientific individualism contribute, namely: “1. partitioning of brain injury survivors and their families, and 2. homogeneous, unitary and normative definitions of family” (Yeates, 2007, p.33). Bowen (2007) has made a case for adapting and translating family therapy approaches for use in community or rehabilitation settings to support both family and client after injury. In particular the narrative techniques of identity work and externalisation are suited to brain injury populations, in the context of an approach that addresses other issues such as: intimacy, communication, problem-solving and positive reappraisal. One potential difficulty highlighted by Johnson and McGowan (1997) and Laroi (2003) is the multi-skilled nature of systemic work with families of people with neurological illness and injury, a commitment that requires extensive amounts of training.

Group therapy
A relational or social roles perspective can be extended beyond family liaison to consider other social systems post-injury. Group therapy has been used in generic and specific brain injury services as a way to;

• facilitate group support,
• work with different systems (such as residential rehabilitation services, families, and carer/cared for dyads),
• make better use of resources.

Evidence from residential brain injury services suggests that group-based interventions are useful for improving;

• family relationships (Kreutzer et al., 2002),

Other literature suggests that group work encourages self expression and the development of personal narratives and meanings (Neimeyer, 1998), and that the facilitator who acts as Observer – Witness plays a key role (Dean, 2004).

Group approaches within community services face significant challenges on a broad level because of poor transport links, finding an appropriate venue, the heterogeneity of group members, and high levels of attrition. These can also be exacerbated by individual injury characteristics such as deficits in memory, information processing and planning that may impact on attendance and the ability of people with brain injuries to synthesise session content (Coetzer, 2007).

Box 1: Service Illustration

Research has highlighted the challenges brain injury poses for parents (Pessar et al., 1993), particularly for male parents showing depression. Their findings also identified compromised parenting performance, characterised by less goal setting and less boundaries, leading to a decreased pace of skill development, combined with less nurturing and emotional support for children (Uysal, Hibbard, Robillard, Pappadopulos, & Jaffe, 1998). Facilitating group support may be one way of addressing these needs.

The case of two fathers who attended a parenting group in South Cheshire will be presented. Neither had taken a prominent role in parenting pre-morbidly, both had difficulty relating to their children and had experienced increased free-time and role shifts following their injury. However, there were also obvious differences between them such as; the number of children they had, their children’s ages, their socio-economic status and access to wider support.

Prior to injury, one of the fathers worked in a factory environment, his wife worked part-time and they had a young daughter. They had a wide social network, but his wife took on the vast majority of the child-care responsibilities. The other father had two daughters, and both he and his wife worked in management roles. His mother-in-law took responsibility for child-care where his wife’s work commitments were restrictive, but again, he had minimal involvement in parenting tasks.

Group intervention

A brief (6 x 1-hour weekly session) group parenting intervention was developed for the purposes of supporting fathers post-injury (Weatherhead & Newby, 2008).
Learning formats included role-play, discussion and homework assignments, as these have been shown to be effective within mainstream parenting classes (for a review, see Barlow & Stewart-Brown, 2000). Examples of the topics covered included:

- Thoughts-Feelings- Behaviour cycle
- Non-directive play
- Child development
- Maintaining a calm state
- Behaviour management tools such as when to use praise & silence
- Parent-child narratives about brain injury

**Evaluation**

Both fathers (and their wives) said that the course had had a positive impact on their relationship with their children, coupled with increased enjoyment and involvement in parental tasks. Furthermore, there was the unanticipated secondary gain of improved behaviour in the children possibly because the fathers demonstrated an improved ability to listen to, engage with and divert the attention of their children. There were some continued difficulties such as impatience, and adjusting communication to the level of their children. However, there were also proud stories of learning to handle the competing demands of 3 year-old and 6 year-old during bath-time, and excitement about teaching their child to ride a bike. One of the fathers said that he was now part of a team with his wife and that he had the confidence to try and solve problems as they arose, rather than relying on his wife to resolve all the difficulties. It is clear to see how the course helped both fathers to move from a previously narrow perspective of their parental role, towards more involvement of their responsibilities and a deeper understanding of what it is to be a father. In short, they had ‘reconstructed their selfhood’.

**Vocational rehabilitation**

When brain injury occurs within working life, a return to work or other meaningful activity is often held as a key benchmark for survivor and family, regardless of the challenges inherent in achieving this. Divorce and separation rates have been shown to be predicted by the employment status of the survivor post-injury (Vanderploeg, Curtiss, Duchnick, & Luis, 2003). Returning to work is central to a number of key processes such as identity reconstruction, psychological and family adjustment, community participation and it contributes to the financial and material resources of a family post-injury. Pre-vocational and/or vocational rehabilitation is offered by several brain injury services (see e.g., DH, 2005), where functional, cognitive and emotional strategies are trialled within a work setting.
However, vocational support necessitates working with a new system of employers, placement providers, job coaches, disability employment advisors and work colleagues, all with varying knowledge of ABI and its consequences. Counter-intuitively, someone’s failure to perform a task following instruction may not be an indication of laziness or an attitude problem. Yet often this conclusion has to be reached without previous knowledge of a survivor or a witnessing of change post-injury. A discourse of ABI sequelae and compensation will struggle against more established workplace talk of productivity, aptitude, application, ambition, confidence, and so on.

Furthermore, difficulties in social communication and interpersonal functioning have been shown to be barriers to successful vocational outcome (e.g. Ownsworth & McKenna, 2004). In a work situation this can also be exacerbated by individual difficulties such as deficits in memory, information processing and planning that may impact on attendance. When these impairments are compensated or minimised through strategies, employers and colleagues are able to witness important competencies and reliability in the survivor of brain injury. This in turn initiates a positive feedback cycle of others then being prepared to provide the injured person more responsibility, witnessing progress over time.

**Wider community networks**

Beyond work, wider social participation has been found to be routinely restricted post-injury. Social isolation has been found to be a common outcome for both survivors and relatives (e.g. Martin-González, 2000), shown to increase over time post-injury (e.g. Brooks, Campsie, Symington, Beattie, & McKinlay, 1987).

Furthermore, specific difficulties in mobility, communication and financial restrictions can be seen to exert particular barriers to the creation of new relationships or maintenance of existing community roles following an injury (Yates, 2003). Given the limited provision of family and community support by brain injury services across the UK (DH, 2005), clinical and neuropsychologists may wish to consider using/collaborating with broader community initiatives beyond service-patient interactions. Examples of these in the UK include community road-shows for people with acquired communication difficulties post-ABI, provided by CONNECT – gatherings created in disparate rural communities where people with similar experiences are brought together to allow new conversations to emerge.

Finally, the latest frontier of conversational and social process to potentially benefit from both clinical, neuropsychological and systemic perspectives post-injury are those
interactions that do not happen in physical space at all – the development of internet use, user-based web-resources, chat-rooms and the growth of cyber-communities for ABI survivors and relatives. ABI websites offering information, signposting professional services and offering online discussion forums are growing and specific examples are now being published and reviewed within the professional literature (e.g., Chiu et al., 2006). More recently, blogs, video narratives and streaming technology, offer further possibilities for the sharing of information and meaning. This development represents a new medium for creating social interaction and possibilities for community, regardless of cognitive and mobility impairments (at home, experiential accounts can be paused, rewound, managed, typed, heard or seen as per the individual’s preferences).

However, some authors have cautioned against the current trends of vast, unstructured, and non-signposted information on the internet (e.g. Parr, Watson, & Woods, 2006), creating barriers within new opportunities for those with cognitive and communication difficulties. A new partnership for clinical, neuropsychology and systemic theory, applied beyond professional-patient dyads, would be to guide the creation and design of web-resources to enhance disability access and navigation.

**Conclusions**

Brain injury has far-reaching implications for relationships and for the relational network of a child or adult who sustains an injury. For a child the network of significant others may include, first the family and then the school, and occasionally other contacts in the community. For an adult, the relational impact of brain injury is often felt in their roles of spouse, parent, work colleague and friend. First there is the direct impact of injury upon cognitive, emotional, social and behavioural functioning, then an indirect effect, from the responses of significant others which has the potential to produce a second injury.

The emerging self of the individual develops meaning and grows through a relational process and the memories of previous repertoires with significant others is a significant component of the construction of post-injury identity. A proactive approach requires that professionals engage in educating significant others about the full impact of brain injury on all aspects of functioning, and working as mediator between systems, for example, between injured persons and their employers.

This article has described the sequelae of severe brain injury in relational terms. This has been achieved by first, highlighting the signs and symptoms that constitute a challenge for social functioning, whether in the family or wider
social systems. Additional sections have focused specifically on couple and family therapy, a parenting group intervention to support parents following brain injury, and the implications of taking a relational approach to vocational and wider community networks. The advent of the internet has dramatically changed the way social networking happens, and overcomes many of the physical challenges that previously prevented wider social interaction.

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Web-links
http://www.jiscmail.ac.uk/lists/tbifamilies.html (A professional network for researchers and practitioners interested in supporting families after brain injury)
www.hipincheshire.googlepages.com (Head-Injured Persons in Cheshire community webpage)
www.ukconnect.org (a community initiative for people with acquired communication difficulties post-ABI)
www.healthtalkonline.org (a specialised health resource).

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