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Why a child's brain injury is a family affair

Sarah Helps

Introduction

This is the story of Tom, his family and my work with them. In it, I plan to illustrate the use of a systemic approach in working with a child affected by acquired brain injury and with his or her family, and some of the components of systemic practice I found particularly helpful in my work. While the starting point of this journey relates to difficulties experienced by and located in the individual, these are experienced and played out relationally. I argue that the stories constructed by the family and the wider system can powerfully influence the recovery of the child.

The start of an unwanted, unpredictable and uncharted journey

Tom (not his real name) was seven when he was knocked over while crossing the road near his house with his dad, by a car travelling too fast. I was told that he had stepped out in front of a car and his dad couldn't reach him to pull him out of the way. He sustained a severe brain injury. (Severity of injury relates to the amount of time during which the patient was unconscious after injury, or the length of time of post-traumatic amnesia. Severe head injury is usually defined as being a condition where the patient has been in an unconscious state for 6 hours or more, or a post-traumatic amnesia of 24 hours or more.) While Tom was in hospital, his family spent many weeks doing 'shift parenting' to ensure there was always one parent at the hospital and one parent available to look after Tom's brother, and to work. They had (or made) no time to talk about and to process their experiences together. They recounted complex medical information to each other, and would become cross when the other had not seemed to understand. At a time when couples and families might need to close ranks and tighten boundaries to make sense of a traumatic event, they were therefore separated, and spent more time with professionals than they did with each other.

After spending a few weeks in hospital, primarily to mend his broken bones, Tom returned home to be looked after by his mother and father. His mother and older brother had been at home when Tom was knocked over and got to hear about the accident from his father, who rang them just minutes after it had happened. They reached him at about the same time as the ambulance.

Tom's family asked me to see Tom some months after the accident because they were worried about how he was coping. He was struggling to concentrate and to learn new information. At school and at home he was moody, found it very difficult to sleep and could be aggressive in what he said to them. In my then role as a clinical psychologist working in private practice, I carried out a neuropsychological assessment, which highlighted how Tom's concentration, planning, problem-

solving and self-regulatory abilities were, at that point, severely compromised.

As I got to know the family and talked about the results of the neuropsychological assessment and how I thought Tom's brain had been affected by the accident, I found myself having more and more conversations with them about how Tom's father was experiencing a range of difficulties, such as poor sleep and struggled to concentrate at work (he had a demanding job and was used to working very long hours and managing highly-pressured situations). Over time, Tom's father described an overwhelming feeling of guilt that he "should have" been able to stop Tom stepping out into the road.

Tom's mother was also full of guilt and harboured very strong feelings of blame towards her husband. She felt very guilty about having these feelings and had not overtly shared with him. The tensions between them became increasingly apparent and, while they both reflected on the deterioration of their relationship to me as individuals, they were terrified of having a conversation that was more 'joined up', for fear this might lead to the end of their marriage. They were both resolute in their determination that Tom should not feel responsible for the breakup of the family.

As I worked with the family, I found Tom's parents had each made sense of the cognitive difficulties resulting from Tom's brain injury in a different way. His father talked about how Tom had always been an impulsive and inattentive child and saw this as one of the primary reasons for him having stepped out in front of the car in the first place. He saw the accident as almost inevitable.

Tom's mother was much more preoccupied by how his future (and indeed her future) had been irrecoverably damaged by the speeding car-driver, and was focused on seeking compensation through the courts, following the drivers' conviction for dangerous driving.

I never met Tom's older brother but was very much aware of him in the house when I visited the family and often wondered how Tom's accident and his parents' responses had affected him.

Working with this family powerfully shaped my interest in ideas about how children who suffered acquired brain injuries and their families might be supported.

Theorising about work with children and families with acquired brain injury

Larner (2009) writes about the theoretical dilemmas of moving between modern and post-modernist approaches to working with children with chronic illnesses and their families. He suggests that, while,

"Modernists espouse a systemic metaphor, use evidence-based and interventive approaches, including strategic,

structural- or solution-focused techniques, and believe in the therapist's knowledge, expertise and power to influence individuals or families to change [...] postmodernists follow a social constructionist, dialogical or narrative paradigm, which identifies the main ingredients of therapy as language, conversation, understanding and the therapist's 'not knowing' stance in eliciting a person's expertise and story" (p. 51).

Larner suggests that many practitioners adopt an integrative, "paramodern" approach, which he construes as an ethical stance. His approach seems to sit comfortably alongside ideas from medical family therapy (Doherty *et al.*, 1994) where a biopsychosocial-systems approach is proposed in working with families who have a member with a chronic illness or disability. Here, the aim is to "integrate mind, body and family in a collaborative systems-oriented treatment" (p. 32).

These two conceptualisations, in turn, sit comfortably with my professional identity as a clinical psychologist, paediatric neuropsychologist and systemic psychotherapist working with children with acquired brain injuries and their families. I have therefore relied on these two collaborative and integrative approaches in both the doing and the describing of the work.

A process of re-connection

During a brain injury, brain cells are destroyed and cannot regenerate. However, the brain has a certain amount of 'plasticity' (an ability for cells that would have done one job to do another) and can to some extent reorganise its functioning, growing new neural pathways using undamaged cells (Ylvisaker, 1998). That the brain tries to develop alternative pathways, networks and links to re-learn the things it could do before the injury and to learn new things, can be seen as isomorphic to the process of the family trying to re-join, reconnect and heal itself in the wake of a life event that has the potential to completely destabilise it.

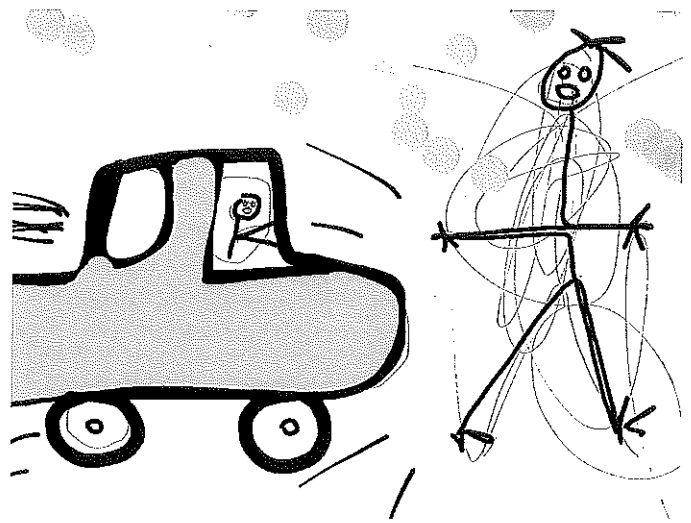
Life cycle interruption

Just like any chronic illness, a brain injury can completely change the typical developmental flow of family life. It can mark an abrupt and highly traumatic transition from one relatively stable pattern of functioning to one in which the previous 'rules' do not work.

In starting to understand the ways in which Tom's family made sense of their world, both before and after the injury, a genogram was useful, not only to map the people important to the child and family but also to bring forth other stories of loss and trauma, which resonated with their current situation. From this, it was possible to 'listen out for' how the family had previously managed challenges to their usual functioning, and to start to track and expand on the shy stories of competence in the face of extreme stress.

Through this process, it was gradually possible to reflect with the parents on the struggles they had negotiated in both their families of origin and in their early life as a couple, and to draw out how their resources in managing previous situations might be used in dealing with the situation with Tom.

In their work with adults who sustained an acquired brain injury, Muir and Haffey (1984) coined the term "mobile mourning" to refer to the repeated grieving process involved



By Thurston

as adults fail to regain their pre-injury functioning. This term seems particularly pertinent for parents of children with injuries, who may repeatedly experience grief along the developmental trajectory as their experiences and expectations of their child's functioning are continually challenged.

Challenges to familiar roles and parenting styles

Although there is relatively little research on the effects of such childhood injuries on families, there is a wealth of research exploring the effects on adults and their spouses and carers. While we need to be cautious in drawing exact parallels, given the lack of a developmental perspective in the adult work, some of the ideas from the adult work can be helpful in thinking about work with children.

For example, research with adults who have sustained a brain injury has suggested that spouses show greater distress than parents, perhaps because it is easier for the parents to revert to old familiar protective roles (Blais & Boisvert, 2005). However, for parents of injured children, it is their familiar protective role that has been disrupted and/or derailed. Usual parenting strategies may suddenly not work any more and, whereas parents ordinarily find the ways in which they manage their children evolve over time, an acquired brain injury can mean that parenting strategies have to change radically and very quickly. For example, Woods *et al.* (2011) found that parents utilised a variety of lax and over-reactive disciplinary strategies in the wake of childhood acquired brain injury, which they suggested could exacerbate the difficulties experienced by the child and the family. While it is not entirely clear how these post-injury strategies related to pre-injury disciplinary strategies, it does suggest that parents might need support to put into place new clear, calm and attuned parenting strategies.

Tom's family described themselves, pre-injury as an ordinary and "well-functioning" family who had never needed or sought any psychological help. They saw themselves as a strong and close couple who had negotiated "bumps in the road" in their journey to becoming a family with relative success. They were skilfully able to reflect on how having children had challenged their expectations of how they had tried to parent their children in different ways to how they

themselves had been parented. However, they felt completely paralysed when their usual calm, discursive disciplinary strategies failed to work with post-injury Tom, as he could not concentrate and attend long enough for them to finish their descriptions to him of what he had done that they did not like.

Therefore, just as the child's brain is constantly evolving along new and sometimes unexpected paths, the strategies that the families need in order to manage and care for their child may also need to evolve and may start to include previously-untested strategies for discipline and praise.

Siblings

Tom's family were thoughtful about their older child, deciding it was best to try not to burden him with their worries about Tom. Their decisions seemed to be related both to how they had evolved their ideas about parenting, involving beliefs about protecting children from stress and to their belief that sharing thoughts and ideas could be more painful than beneficial. However, in retrospect they came to think that this had an unexpected effect of isolating their son at a time when he, like many siblings in this position, could have benefited from being involved as much as he wanted to in discussions, planning and rehabilitation.

Burnsall (2003) described how, after the injury, parents could become overprotective, or struggle to make time for healthy siblings. She also described how siblings may resent that they have to do things on their own that they would previously have had help to do, or may feel they need to remain strong as everyone else around them is struggling to cope. Siblings may also have to take on novel care-responsibilities and may, in general, experience high levels of distress (Orsillo *et al.*, 1993).

Although not available when I worked with Tom and his family, fantastic resources for siblings now exist such as the sibling pages on the Brain Injury Hub website.

Families make meaning of acquired brain injury

It is not only what happens to the child's brain as a result of an injury that affects their rehabilitation, but also the meaning made of it by the child, the family and the wider system.

The careful questioning-processes that family therapists will often use to explore the perspective of family members can be very helpful in meaning-making and meaning-sharing. With Tom's parents, circular questioning, both with each parent individually and in our rare joint conversations, enabled them to start to become more aware of their own thoughts and feelings, and those of Tom and Tom's brother as well as important people (their own siblings and parents) in the extended family network, and how the ideas of others affected how they understood and managed Tom's difficulties. For example, one of the grandparents saw Tom as now "getting away with a lot", which had the effect on Tom's parents of increasing their feelings of guilt when they did not challenge every behaviour that would previously have been reprimanded. In turn, this connected with their shared

experiences of having been brought up in families where children were "seen and heard only a bit".

In writing about adults, Flynn *et al.* (in press) highlight how individuals can experience a loss of self, following the pivotal moment of the injury when their lives changed. For children as young as Tom, ideas about the self are still very much in development, although it was clear he had clear thoughts and feelings about how his identity had been compromised as a result of the injury. Tom's parents gave rich descriptions of their views of how Tom's identity had, as they saw it, undergone tremendous change. At the time of my intervention, they could not see any future in which Tom's identity would not be dominated by narrative of injury and loss. Flynn *et al.* highlight how, for adults, a brain injury creates "an undercurrent into the rest of your life" and, over time, Tom's parents were occasionally able to see the injury as an undercurrent rather than a totally dominating story.

Linking with wider systems

It is not uncommon for parents to feel powerless and without a voice in the face of acquired disability or other childhood illnesses (e.g. Bradford, 1996). This perceived powerlessness can restrain their ability to contribute within professional systems. Tom's parents shared a strong belief in the importance of medics and allied health professionals as experts telling them how to be with their recovering son. While their faith in the large medical team that had started to 'mend' Tom was helpful, it also seemed to stifle their ability to relate what they knew of their son. During meetings with the medical team and the parents, my interventions were designed to slow down the process a little and to encourage using the parents as a resource rather than a potential interference in the process of rehabilitation.

In working with school staff who were looking forward to having Tom return to school, teachers became stuck on the idea of "Isn't it great he is alive". This was in direct contrast to the beliefs of the family who were fixed on the fact that their child looked the same but was not, to them, the same person. This sense of being the same but different is clearly articulated by adults who have sustained a brain injury. The increasing tension between school staff and the parents created a block to their being able to communicate in a meaningful way to share ideas about how to best meet Tom's needs. Professionals meetings, designed not to exclude the family but to offer space for teaching staff to air their beliefs about how Tom was making progress at school and what they, at times, saw as his new-found laziness (not an uncommon thought after acquired brain injury, when children can cope with some tasks and not others, and generally can be more affected by fatigue) were useful. Within these sessions, I used both expert and 'not-knowing' positions in both offering facts about the impact of an acquired brain injury and exploring the meanings of the facts. Useful educational resources have now been produced to help teachers understand the needs of a child both at a brain and a systems level (e.g. Walker & Wicks, 2005).

In retrospect, creating a context in which resonances could have been explored would have been useful, but seemed outside the scope of this particular piece of work.

The story so far

By the time I stopped working with Tom's family, there was no magical resolution. Tom's difficulties as a result of the injury were becoming more pronounced as his prior learning and knowledge had stopped stretching sufficiently to mask how hard it was for him to take in new information. His school had started to accept that just holding on to 'being alive' was, in fact, starting to cheat Tom out of specialist support and interventions that might help him fall less far behind his peers. Tom's parents started to have some conversations about their feelings and, in small ways, started to talk to each other about how their anxieties and anger had got in the way of communicating so as to support each other. Tom's brother remained an enigma to me.

Practice and policy has moved forward in recent years, and there has been widespread acknowledgement that families are central to the process of rehabilitation. In 2003, The British Society of Rehabilitation Medicine produced guidelines on rehabilitation after acquired brain injury. These highlight how, "family members can be a crucial asset to the patient, providing both long-term support and a major contribution to the rehabilitation process" (2003).

What might help in practice?

The following is a (very much non-exhaustive) list of the ideas and practice parameters I have found useful in working with families of children who have sustained an acquired brain injury:

- Family therapists need to have a good-enough understanding of the specific range of impacts of childhood acquired brain injury in order to be aware of some of the areas that might need to be explored, such as impact on cognition, educational achievement, behaviour, emotional regulation and personality
- Engage with all members of the family and significant support network, directly or indirectly via genograms and tracking intergenerational patterns
- Explore the beliefs and behaviours of all family members regarding the nature and causes of the injury, the ongoing journey through rehabilitation and how these beliefs relate to how they see their role
- Help families develop and articulate their shared and non-shared understandings of the range of impacts of the injury for the child
- Pay attention to the GRRAACCEESS (Burnham, *et al.*, 2008) and particularly to issues of power and powerlessness for both the child and family, and support families to use their knowledge of their child as a resource in dialogue with wider systems
- Engage with systems around the child and family and gently explore the beliefs and prejudices of the multidisciplinary,

multiagency system, which might have the potential to create stuckness.

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