

Family Life And Brain Injury

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Brain injury continues to be one of the leading causes of death and disability in North America (Greenwald, Burnett & Miller, 2003). It can happen to anyone, young or old, during a variety of activities. Brain injury can have life altering changes on the person injured, and is now recognized to cause significant distress and change for the family and friends of the person injured.

In Ontario brain injury occurs at a rate of approximately 18,000 per year (Ontario Brain Injury Association, 2004). In Canada, it has been reported that approximately 50,000 people per year are hospitalized with brain injury (Newfoundland Brain Injury Association, 2002). In the United States, the annual incidence of brain injury is estimated at a rate of 250-300 per 100,000 population or 1.5 million per year (Campbell, 2000). At this rate, the city of London, Ontario alone may have more 750 brain injuries per year.

Approximately half of brain injuries are reported to be caused by motor vehicle accidents, and 80% are reported alcohol related (Newfoundland Brain Injury Association, 2002). Twice as many males as females experience brain injury. More than 50% of people that experience brain injury are men between 15 and 30 years of age. More than 50% of the people that experience brain injury are under the age of 20 years.

However, it is not just young males with risky behaviours that experience brain injury. Each year over 5000 children in Canada experience brain injury from bicycle accidents. Brain injury can happen to an elderly person while falling down the stairs. Brain injury can happen to both genders, young or old, in a variety of settings. Brain injury in Canada is a significant issue, for people with injury, families, friends and others trying to provide their care.

Although brain injury is typically classified by level of severity, injury to the brain can affect control and monitoring of physical, cognitive, behavioural, and emotional functioning (Newfoundland Brain Injury Association, 2002). The brain controls heart rate, breathing, blood pressure and swallowing, and injury to the brain can be life threatening.

One of the functions of the brain is to help assess what is going on outside of the body, so that the person can act and interact in their environment. The brain helps to assess what is happening, to process this information, to compare this information to similar experiences encountered, to decide which action to initiate, to carry out the intended action, to monitor and assess the action, and to store the results into memory for future use. Injury to the brain can affect these functions (DePompei, Blosser, Savage & Lash, 1998) and affect how people behave, including how they behave and interact with family, friends and other caregivers.

Practitioners in the hospital and community rehabilitation environment are familiar with the course of events after a motor vehicle accident brain injury. People with brain injury, and their families, typically experience the process for the first time. After injury the person injured is usually transported by ambulance to an acute care hospital. They may undergo surgery but are soon transferred to a rehabilitation hospital for more in patient care and therapy. After multi disciplinary in patient treatment, people with brain injury are discharged home. Once home, community rehabilitation providers start to treat and interact with both the person with injury and their family. Family members may or may not be ready at this stage, but are often required, to provide care to people that have been injured.

When brain injury happens to a loved one, family members can find themselves struggling to cope with the impact the injury has on their own lives. For example, brain injury to a pre accident academically gifted child who now has difficulty doing basic arithmetic, can have significant impact on the emotional or psychological well being of a parent.

Brain injury to the sole breadwinner of a family, can cause family members stress and worry over how the family will financially support itself (Williams, 1991). In a single income family, a pre injury stay at home mother may be required to re-enter the work force and become the breadwinner for the family. Pre injury plans may need to be modified and family members may need to learn new ways to survive. Family members often need both the capacity to provide care to the person injured, and ability to adjust their own lives.

The family member without injury, may not have the skills needed to return to the work force. They can now be faced with the task of preparing for work while trying to deal with their own emotional, providing care to the injured person, all in the midst of family dysfunction. The situation is often not easy for families to deal with.

Researchers have documented that there is long term psychological distress for families after brain injury (Lezak, 1986; Gan & Schuller, 2002; Muray, Maslany, & Jeffery, 2006; Gan, Campbell, Gemeinhardt & McFadden, 2006). Families can experience denial, guilt and anger after brain injury to a family member. The family may question why the accident or injury happened to their family? The feelings and emotional turmoil that families experience, can go on for years after injury. It is clear that the injury affects not only the person that has experienced injury, but often affects many if not all members within the family. Researchers have reported that individuals with brain injury, their mothers, spouses, siblings and the family unit, all have more family distress after brain injury as compared to norms (Gan, Campbell, Gemeinhardt, & McFadden, 2006).

Following brain injury, there may be persistent behavioural changes to the family member with injury. The person may not respond to treatment as fast as or as well as hoped and families can question their own adequacy as caregivers. Family member can blame themselves for lack of progress or outcomes. Care for the person with brain injury is often provided by parents, spouses or other family members, who may not be well prepared to provide care.

There may be anger directed at the family member with brain injury. There may be anger at other family members, a spouse, a child or a sibling, who may not be coping well with losses and changes in the family system. Family members may not function well individually, or the family as a whole may not function well. Brain injury can affect the entire family system.

Denial is often present after injury. As an emotion, denial can be helpful and harmful to families. Some families that deny potential for negative outcomes may put forth extra effort to access resources for the injured family member. The extra effort may help the family member reach maximal recovery. However, for families that deny permanent impairments or significant post injury changes, denial can cause families to have unrealistic expectations for the future. The emotional distress can promote prolonged family dysfunction.

Role changes often occur within the family system. Pre injury, parents typically expect children will become more independent as they mature through teenage years. However, after brain injury parents may be required to provide much longer term care to their children than they had planned before the injury. Some parents may need to alter their retirement plans, in order to provide care and support to their children. Expectations and roles for siblings may change after injury.

Care giving needs can restrict families from pursuing their own activities. Family members may need to alter their pre-injury lifestyle. Supports that existed pre-injury may disappear. Families may become socially isolated after a family member experiences brain injury.

In Ontario, families providing care to a family member as a result of an automobile accident, may receive insurance funding to do so (Government of Ontario, 2008). Some families may even be able to recover financial cost of providing care through the tort system. This "benefit" can provide some financial relief to families caring for injured family members. However, even with attendant care benefits and tort recovery, after brain injury many families can face emotional distress, financial hardship and family dysfunction.

After having provided case management and counselling in the Southwestern Ontario rehabilitation community for several years, I can offer that in recent years, access to information and availability of services to help families after brain injury has improved. However, for some families, for example those that fall through the cracks in the system or those in rural communities, there can still experience lack of access to information and support services. Some families continue in distress with little help.

After brain injury, some families learn to cope well. They make adjustments and they learn to function. Other families are not as resilient or lucky. Some families do not remain intact and some struggle with ongoing family discord (Williams, 1991). One partner may decide to leave. Some parents may not be able to cope with the intensive care giving needs. Relationships between partners and children can be forever changed. Relationships between parents and non injured children, and relationships between siblings can change. Families are often faced with altered relationships and ongoing stress.

Counselling for families and individual family members can be helpful after brain injury (Kosciulek, 1995). I have observed in my own case management and counselling practice, that counselling has helped many families after brain injury. Published clinical guidelines (Muir, Rosenthal, & Diehl, 1990) suggest that families may require counselling help with anxiety and guilt, and to recognize their self worth and competence. Families may need to learn to use their individual strengths and to draw on each other for support. When needed after brain injury, counselling has the potential to help some families cope and rebuild their lives.

However, some families may not been ready to deal with the potential emotional pain that can come with counselling. They may prefer to try to continue to meet their own needs and to counsel independently, in spite of the distress that they may be experiencing.

The issue of whether to involve the family member with brain injury in family counselling needs to be addressed (Kosciulek, 1995) by the family and counsellor. If the family member with injury is able to participate in counselling, can explore, gain insight and understanding from the counselling, then involving the family member can be helpful. Some family members may need individual counselling, to express and explore issues too difficult or uncomfortable to divulge in family groups. Group processes can be helpful, but individual counselling to family members and the person with injury, may also be required.

Families may require help to develop appropriate support networks in the community. The London Brain Injury Association (2008) has received 2 years of funding to offer monthly support groups to survivors and families in a number of locations in Southwestern Ontario. This community support can be tremendously helpful to families with brain injury. Many health providers in the many community rehabilitation agencies, psychologists, psychotherapists, counselors and social workers, are often prepared to help families deal with changes after brain injury.

Counselors can help families develop peer and natural supports. Without taking anything away from the professionals providing rehabilitation care, some families can benefit from the families that have dealing with similar experiences and challenges who are willing to share their knowledge. The families that have struggled, and those that have survived and grown, may have the potential to help families in need.

After brain injury, once survivors and families have had a chance to grieve and adjust to their loss, families learn to create and tell new stories about themselves. In spite of their ongoing distress, they develop new scripts and schemas, learn new ways to cope and function. Families learn to care and interact with the person injured, with other family members, and within their communities. They continue to live and love. Families create new histories as they provide care and go about their lives. The experiences they encounter create new understanding. For people with brain injury that have survived, and for their families, life is dynamic, not static and will continue to change.

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About the author:

Jamie Campbell is Director, Rehabilitation Services, at Rehab First Inc. He has been providing case management, counselling, vocational rehabilitation and future care cost services to the legal and insurance industries since 1981. He has significant experience helping people and families that have experienced acquired brain injury, spinal cord injury and psychological distress. His full curriculum vita is attached with this report. For 16 years, Mr. Campbell was the President of Associative Rehabilitation Inc., a disability management firm that provided various rehabilitation and medical services across Canada and the United States. He was employed as Vice President, Insurance and Institutions, at Aetna Health Management, a subsidiary of the insurance company Aetna Canada. He has graduated with the M.Ed. (Counselling of the Psychology), M. Ed. (Educational Psychology/Special Education) and M.B.A. degrees from the University of Western Ontario. He has completed training seminars and graduate level courses in case management, rehabilitation, research, assessment and counselling. Mr. Campbell is a Rehabilitation Certified Rehabilitation Counsellor (CCRC) through the Commission on Rehabilitation Counsellor Certification (CRCC), a Registered Rehabilitation Professional (RRP) designated by the Canadian Association of Rehabilitation Professionals (CARP), a Canadian Certified Counsellor (CCC) through the Canadian Counselling Association, and holds the Canadian Certified Life Care Planner (CCLCP) designation through the Commission on Health Care Certification (CHCC).