Brain Injury Association Canada 11 July 2008

Brain Injury and Women

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Réseau des femmes handicapées du Canada

Anecdotal

- A middle-aged lady goes to her GP after several weeks/months of forgetting things — basic daily chores and basically having a left side deficit. She probably wouldn't have made a specific appointment for these things — and she certainly didn't call them ''deficits'' or even "symptoms". She went for another reason (a prescription refill I believe) and mentioned this during the appointment in conversation.

- Her GP continued the conversational tone regarding her comments, telling her that "she was going through the change". So she should go home and take up knitting.

- She had fallen and hit her head some months previously. But her GP dismissed her obvious symptoms of brain injury.

Anecdotal

- A young woman this time, in her 20’s or 30’s - went through a neuro-psych exam after a severe brain injury. Nothing showed as being drastically changed — at least not in the subjects that were covered by the neuro-psych testing. Her numerical skills showed deficits, but not much else - so she considered herself to be relatively lucky.

- Until, later at home, she tried to sew — she was covering a blanket with a sheet. (Some Nova Scotians refuse to believe anything is worn out!)

- The sheet needed to be added to on either side because it wasn’t wide enough to cover the blanket. She couldn't "see" how the materials were going to fit together. Or how to sew the pieces together - which side was going to be the outside and which was going to be the inner side. She had a panic attack and has been feeling quite inadequate since then as if she were an imposter.

The Impact of Female Reproductive Function on Outcomes After Traumatic Brain Injury

- This study attempted to determine the impact of traumatic brain injury (TBI) on female menstrual and reproductive functioning and to examine the relationships between severity of injury, duration of period stoppage (amenorrhea), and TBI outcomes.
- It was found that the median duration of stopped periods (amenorrhea) was 61 days (range, 20--344 days). Many subjects' menstrual function changed after TBI, reporting a significant increase in skipped menses post-injury and a trend toward more painful menses.

Reproductive Effects

- More severe TBI, as measured by the duration of posttraumatic amnesia, was significantly predictive of a longer duration of stopped periods (amenorrhea).
- Study Conclusions: The severity of TBI was predictive of the duration of amenorrhea (menstrual period stoppage).

Reproductive Effects

- A shorter duration of amenorrhea (menstrual period stopping) was predicative of better ratings of global outcome, community participation, and health-related quality of life post-injury

- **Source:** ***The Impact of Female Reproductive Function on Outcomes After Traumatic Brain Injury - by Ripley DL, Harrison-Felix C, Sendroy-Terrill M, Cusick CP, Dannels-McClure A, Morey C. (Obtained from Physical Medicine and Rehabilitation, Vol 89. Issue 6. June '08. p.1090-1096.)***

Estrogen

- a contraceptive pill ingredient - as well as being the female hormone - has been found to improve the outcome of survivors with severe brain injury according to a study reported in the online journal, BioMed Central's Critical Care. It was a randomized, double blind trial of 159 patients with acute severe brain injury. (The press release I read did not indicate whether all of the patients were all female or not.) Significantly more patients who were given progesterone had favourable neurologic outcomes compared to those given a placebo. Progesterone was also linked to increased survival at 6 months.

Stigma

- Everyone has experienced or seen the stigma that accompanies brain injury. The book *Dissonant Disabilities* (Driedger, Diane and Owen, Michelle, Women's Press, Toronto, 2008) defines stigma as attributes that "reduce individuals from a whole and usual person to a tainted discounted one".
- A stigmatized individual starts to fail to receive the respect and regard they would have received before the stigma. Attempted correction of this external perception is often attempted - although it is mostly not possible with brain injury. Because a brain injury affects a person's physical, psychological and social identity. (p.88)

Victimization of Persons with Traumatic Brain Injury or Other Disabilities: A Fact Sheet for Professionals (National Center for Injury Prevention and Control)

- According to the U.S. Department of Justice (2004), victimization occurs when "… a person suffers direct or threatened physical, emotional, and/or financial harm." Victimization can include physical violence, sexual violence, psychological or emotional abuse, and neglect.

The Extent of the Problem?

- Persons with disabilities are 4 to 10 times more likely to become a victim of violence, abuse, or neglect than persons without disabilities (Petersilia 2001). That is an American statistic.

- Stat Can 2005 reports that the prevalence of abuse is 1.5 to 10 times more than for nondisabled women. For further stats see www.pcawa.org/wap3.htm.

- * Similar proportions of women with and without disabilities report having experienced episodes of victimization (Sobsey and Mansell 1994). Women with disabilities, however, report greater numbers of perpetrators and longer time periods of individual episodes than women without disabilities (Young et al. 1997).

Where does Victimization Occur?

- Victimization usually happens in isolated locations where a person with disabilities has little or no control of the environment (Sobsey and Mansell 1994), and the setting is away from the view of law enforcement (Verdugo and Mermejo 1997).

- Victimization especially occurs in institutions –which is where people with disabilities have traditionally been housed.

Who Commits Acts of Victimization?

- More men than women, either as intimate partners or as health care workers (Brown and Turk 1994; Marley and Buila 2001), are reported to commit acts of victimization against persons with disabilities.
- * Family while caring for a relative with disabilities (Milberger et al. 2003; Stromsness 1993).
- * Personal home care attendants (Oktay and Tompkins 2004; Saxton et al. 2001) or health care workers at institutions (Brown and Turk 1994; Sequeira and Halstead 2001) have been reported to perpetrate abuse and violence against persons with disabilities.
- * In institutional settings, persons with disabilities may commit acts of physical violence or sexual violence against other persons with disabilities (Sobsey and Doe 1991).

What Factors Make a Person with Disabilities Susceptible to Victimization?

Societal Factors:

- Misperceptions about disability include ""having a disability protects a person from victimization""; the risks to a person with disabilities are thought to be less than the risks to a person who has none (Young et al. 1997).
- Unemployment or underemployment of persons with disabilities restricts their income and limits their choices for caregivers, leading to an increased risk of victimization (Stromsness 1993).
- Lack of money often causes persons with disabilities to live in areas where crime rates are high and the potential for physical and sexual violence is greater than in wealthier neighbourhoods (Curry et al. 2001).

Community Factors:

- * Community resources for victims of physical and sexual violence, emotional abuse, or neglect are usually designed to assist people without disabilities (Swedlund and Nosek 2000; Chang et al. 2003; Cramer et al. 2003). Organizations that provide such resources do not routinely collaborate with organizations that assist persons with disabilities (Curry et al. 2001; Swedlund and Nosek 2000; Chang et al. 2003).

  DAWN Canada is conducting a survey this year to determine if transition houses across Canada are accessible for disabled women and their children escaping abusive situations.

- * Health care (Swedlund and Nosek 2000; Chang et al. 2003; Cramer et al. 2003) and law enforcement (DOJ 1998) professionals are frequently uninformed about victimization of persons with disabilities. Thus, they may not have the specialized knowledge or skills to identify and assist these individuals.

What Factors Make a Woman with a Traumatic Brain Injury Susceptible to Victimization?

Relationship Factors:

- Persons living with a TBI often have difficulty with anger management, which may prompt others to use undue physical force or inappropriate medication (Kim 2002).
- Misperceptions about TBI and its effects may lead to treatment that is demeaning or abusive (Sequeira and Halsted 2001).
- TBI outcomes affect others' perceptions of a person's ability to honestly and accurately report an incident of victimization (DOJ 1998).
- Persons with TBI or other disabilities may experience physical and sexual violence, emotional abuse, or neglect by a caregiver in return for access to medication, adaptive equipment, or assistance with activities of daily life (Oktay and Tompkins 2004).

Individual Factors

- A TBI can cause cognitive problems that reduce one's ability to perceive, remember, or understand risky situations that could lead to an incident of physical or sexual violence (Kim 2002; Levin 1999).
- Persons with a TBI may engage in at-risk drinking or drug use that place them in situations or relationships that lead to episodes of victimization (Kwasnica and Heinemann 1994; Li et al. 2000).
- In some persons, a TBI causes uninhibited behaviours that lead to risky sexual engagement, exposing them to HIV/AIDS or other sexually transmitted diseases (Jaffe et al. 2000; Kramer et al. 1993). It raises a female's self-esteem - that someone wants to spend time with her, is interested in her and what she has to say. Unfortunately a survivor who has lost the ability to "read" social clues is an easy mark for sexual aggression by another person.

Impact on Women

- J Trauma 2004 Feb; 56(2): 284-90 - *The impact of major trauma: quality-of-life outcomes are worse in women than in men, independent of mechanism and injury severity* - by Holbrook and Hoyt - says "These analyses provide further important and more detailed evidence that women are at risk of worse QoL outcomes and early psychological morbidity after major trauma than men, independent of mechanism and injury severity."

Impact on Women

- Arch Phys Med Rehab 2004 Mar; 85 (3): 376-9 - *Sex differences in injury severity and outcome measures after traumatic brain injury*- by Slewa-Younan, Green, Baguley, Gurka and Marosszeky - says "In the present study, men's levels of injury severity were greater than women's despite the same admission criteria (high-speed MVC) being applied to both sexes."

Impact on Women

- Brain Inj 2008 Feb; 22(2): 183-91 - *Do men and women differ in their course following traumatic brain injury? A preliminary prospective investigation of early outcome* - by Slewa-Younan, Baguley, Heriseanu, Cameron, Pitslavas, Mudaliar and Nayyar - says " This study indicated that, after matching for initial injury severity and age at injury, women with severe TBI demonstrate a better early outcome than men."

Retraining Cognition: Techniques and Applications - 2nd ed (2003) by Rick Parente and Douglas Herrmann, Pro-ed: Austin, Texas.

- p.14 A person's health considerations include the degree to which she is free of physical or emotional disease or any other debilitating condition or malady. These problems can cause a client pain, which, in turn, limits his or her cognitive processing. Even routine disruptions of health, such as the common cold, impact cognition.
- In short, a person's physiological condition affects their thinking and memory. Only in recent years has science begun to identify the chemistry of cognition (Squire L., 1985, "Memory and Brain", Oxford University Press: New York)

Retraining Cognition: Techniques and Applications - 2nd ed (2003) by Rick Parente and Douglas Herrmann, Pro-ed: Austin, Texas

- p.14 A person's attitudinal state includes their emotional disposition to process different kinds of information or to interact with different people. Progress in therapy can be greatly improved when the therapist is similar to the client - the same sex and/or the same age, etc. As well, a person is likely to perform better when their attitude toward a task is positive.

- Depression and/or stress and/or high anxiety can interfere with thinking and memory. Stress is associated with impaired memory for everyday information. (Fisher S. & Reason J.T. (Eds.) 1986 A Handbook of Life Stress, cognition and health. New York: Wiley.)

p. 60 Parente R. and Anderson-Parente J.K. Retraining memory: techniques and applications Houston: CSY. (1991) described successive therapeutic steps of recovery

- Stage 1: Arousal - Orientation which occurs just after a coma. Goal is to orient the person in time, to person and place.

p. 60 Parente R. and Anderson-Parente J.K. Retraining memory: techniques and applications Houston: CSY. (1991) described successive therapeutic steps of recovery

- Stage 2: Attention and Vigilance - being able to focus, concentrate and perform

p. 60 Parente R. and Anderson-Parente J.K. Retraining memory: techniques and applications Houston: CSY. (1991) described successive therapeutic steps of recovery

- Stage 3: Mental Control - repetition training and strategy use

p. 60 Parente R. and Anderson-Parente J.K. Retraining memory: techniques and applications Houston: CSY. (1991) described successive therapeutic steps of recovery

- Stage 4: Rehearsal - the ability to maintain information in memory long enough to make the information available and accessible in the future

p. 60 Parente R. and Anderson-Parente J.K. Retraining memory: techniques and applications Houston: CSY. (1991) described successive therapeutic steps of recovery

- Stage 5: Recovery of Episodic Memory - episodic memory is remembering novel aspects of one's life (p.48). E.g. what you had for breakfast this morning, or what shoes you wore yesterday.

p. 60 Parente R. and Anderson-Parente J.K. Retraining memory: techniques and applications Houston: CSY. (1991) described successive therapeutic steps of recovery

- Stage 6: Higher Order Cognition - involves leaning how to reason, solve problems, make decisions, set goals and prioritize (Sternburg R.J. and Smith E.E. 1988 *The psychology of human thought,* Cambridge, United Kingdom: Cambridge University Press)

p. 60 Parente R. and Anderson-Parente J.K. Retraining memory: techniques and applications Houston: CSY. (1991) described successive therapeutic steps of recovery

- Stage 7: Recovery of Social Competence - affects a person's social life. Learning/re-learning to recognize social clues in a conversation (e.g. someone checking their watch)

Also related to these stage 7 factors;

- As explained in "Case Study of the Brain Injury Association of Nova Scotia: An Entrepreneurial Non-profit" (Warren, 1999), this is possibly due to the fact that although they can function reasonably well when performing regular daily activities, "they still have significant, although subtle, impairment of thinking function".
- That impairment of function might result in not thinking about the consequences of her actions. For example, going for a ride with a stranger, with on way to return
- Not thinking of the possible result (s) of sex - pregnancy, disease, injury, etc.

p. 60 Parente R. and Anderson-Parente J.K. Retraining memory: techniques and applications Houston: CSY. (1991) described successive therapeutic steps of recovery

Factors affecting successive therapeutic steps of recovery:

- Impaired attention - which involves being easily distracted. For example being distracted by movement in the background, or background sound - or what should be background, movement and sound. That is poor focus.
- Can also be the inability to pay attention to two things at once or in alternation - which is poor control over shifts of focus
- Or difficulty in remaining vigilant (vigilance is defined as maintaining one's attention).

Factors for Women

- Women are usually better at multi-tasking than men. A new mother, for example, has to get the hang of watching the baby while preparing supper - and maybe supervising another child at their homework or playing - and maybe talking on the phone at the same time.
- A brain injured young mother will have to overcome her impaired attention span to be able to return to that level. The stresses that come from being anxious over whether the child/children are all right can impair memory for everyday information (Did I put the salt in the casserole? Or, when did I turn the oven on? Fisher and Reason (1986) say that depression and/or stress along with high anxiety can interfere with thinking and memory.
- (Fisher S. and Reason JT (eds) 1986 "*Handbook of Life Stress, cognition and health*". New York: Wiley.)

Factors for Women

- Because we live in a world where body perfection - especially the female body - is the highest goal possible for many people, women's body's are not acceptable when they are limited by some handicap (Driedger and Owen, 87 and 89).
- I asked questions in an online brain injury chat room - to find out more of the problems that affect female survivors. The answers were immediate - but they mostly concerned bodily functions. So the answers were not particularly unique to women. They were: hormonal concerns; sleep changes; and it is harder to stay balanced.
- The fourth answer brought about some further conversation - it was "missing with make-up due to tremors". The lady was referring to lipstick. (I had immediately thought of eyeliner and eye shadow.) She said she doesn't wear makeup anymore.

Stages of Grief

- Before acceptance of a changed body - due to the effects of a brain injury - the survivor goes through some or all of the stages of grief as expressed by Elizabeth Kubler-Ross:

Denial Anger Bargaining Acceptance

- It is grief for the person and her life that was pre-brain injury.

Final Thought From Helen, an Australian Stroke survivor

What would you say to someone who has had a brain injury or a stroke?

I would just try to encourage people. Yes, it is difficult. Every day is going to be a battle. Life possibly is not going to be the same again, but there is tremendous support available for people. When you are down, try and lift yourself up. Of course, you will have down times, but be encouraged that people can, and do, go on and make recoveries. Alright, our lives aren't what they were before. We are going to experience tremendous suffering and difficulties, but we are the same people, people of value, people to be loved and people who can contribute, even though it might be in a very different way to the way it was before.

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pspages/ps_stroke?open