



Recognizing and Understanding Ambiguous Loss

**An Avenue for Family Healing and Implications for
Professional Health Care Practice**

By

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Statistics for Acquired Brain Injury (ABI) - 2004

- Prevalence Rate (current population managing an ABI)
 - USA: 587,310 pop of 293,655,405
 - Canada: 65,015 pop of 32,507,874
- Incidence Rate (number of new cases)
 - USA: 342,006 pop of 293,655,405
 - Canada: 37,860 pop of 32,507,874



Statistics

- Brain injury is the # 1 killer and disabler of people under 45
- The cost to society is huge. Brain injury alone costs Canadians more than \$ 1 billion per year
- MPIC (2005) – 3,000 Manitobans per year suffer from a brain trauma



Current Research

- An extensive body of literature provides firm evidence that brain injury harms families subjecting them to significant burdens and stress.
- (Kosciulek & Lustig, 1999; Wells et al 2005; Ponsford et al 2003; Allen et al 1994; Gan et al 2006; Man et al 2002; Mauss-Clum & Ryan, 1981; Degeneffe, 2001)



Research cont'

- Caregiving burden can actually increase over time
- Caregivers have reported more difficulty dealing with cognitive, behavioural, and neuropsychological changes than with changes in mobility or physical functioning.
- (Minnes et al 2000; Godfrey et al 2002)



Research con't

- Gan et al (2006) concluded the majority of research to date focused on the primary caregiver
- From the family systems perspective it is inadequate to only consider the experiences of the person with the injury and the primary caregiver



Research cont'

- Researchers and Family Respondents are strongly recommending a need for **family systems treatment** that can provide support to families **throughout** their **ABI** experiences.
- (Gan et al 2006; Boschen et al 2007; Haigler et al 2004 Ponsford et al 2003; Murray et al 2006)



A Joining Together

- Ambiguous Loss Theory may be a useful model for supporting families as they live their lives with a member who has an ABI.
- Landau and Hissett (2008) demonstrated that even a mild brain injury could lead to experience of ambiguous loss
- Kean (2010) explored families' experiences with critical ABI illness – findings – emergence of an ambiguous loss process



Ambiguous Loss

- Genesis: Family Stress Model – Hill (1949, 1958) – McCubbin and Patterson (1983) – McCubbin and McCubbin (1989) – Antonovsky (1996) – Boss (1987) – Boss and Couden (2002)
- Boss, P. (2006). *Loss, Trauma, and Resilience – Therapeutic Work with Ambiguous Loss* (1st ed.). New York: W.W. Norton



Ambiguous Loss

- Unclear Loss
- Physical Absence with Psychological Presence OR
- Physical Presence with Psychological Absence
- Is not one particular event
- Is an ongoing situation that has no closure



Ambiguous Loss

- Most stressful as it defies resolution and creates long-term confusion about who is in or out of the psychological family. (The definition of family can greatly vary: peers, friends, only certain family members not others, neighbours)
- Creates a powerful barrier to coping and grieving and leads to symptoms such as depression and RELATIONAL conflict that can erode human relationships



Ambiguous Loss

- People do not “get over” such loss as this
- Can be highly stressful
- Ambiguous loss is a relational condition (because it is about relationships), therefore a relational intervention is needed



Ambiguous Loss

- People who are physically present but psychologically absent are often denied their emotions and expected to act as they always were, or they are prematurely extruded from the system and treated as if they are already dead or gone



Ambiguous Loss

- Family members attempting to cope with a member who is physically present but psychologically absent struggle with their own private grief emotions, attempt to resolve how this member “fits” and try to cope with the significant differences.
- The certainties in a relationship are unachievable if a person who is cared about is neither clearly absent nor present.



Ambiguous Loss

- Parents and caregivers may be less able to separate their own life situations from those of the affected member.
- Parents and caregivers may take on too much responsibility for aspects of the affected person's life.



Recognizing Ambiguous Loss

- Immobilization
- Inability to define the problem resulting in a lack of action
- Feelings of helplessness and hopelessness
- Blocked coping
- Sense of isolation from others
- Symptoms of depression



Recognizing cont'

- Anxiety
- Physical exhaustion
- Emotional exhaustion
- Denial or selective attention to one aspect of the situation
- Express feelings of guilt and disloyalty
- Withdraw from the affected individual, peers or others



Ambiguous Loss

- I believe this concept is critical to healing in the process of resiliency.
- Needs to be acknowledged, identified with families and spoken of by professionals.
- Professionals need to move beyond the medical and individual models and recognize that clients and their family members may be experiencing ambiguous loss.
- The 'art' of caring



Ambiguous Loss

- Professionals need to incorporate more direct family involvement in the medical treatment process
- Inclusivity denotes respect
- Not every family needs professional treatment, however through inclusion and speaking about ambiguous loss, professionals will help families to identify their beliefs about health, sickness, recovery, hope, hopelessness as these are the building blocks of healing and resiliency



Treatment

- Narrative/Dialectical
- Not to produce solutions
- It is a process of learning to tolerate the ambiguity
- Building and sustaining resiliency
- Increase the comfort of individuals and family members



Ambiguous Loss

- Therapeutic Goals
 - Emphasizes RESILIENCE and HEALTH
 - RESILIENCY is a PROCESS that takes time
 - FAMILY REILIENCY is the path the family follows as it adapts in learning to TOLERATE the ambiguity



Ambiguous Loss

- Therapeutic Goals Cont'
 - Ability to live comfortably with the ambiguity
 - Cont' with normal functioning and an ability to maintain a stable equilibrium no matter what
 - An example of blockage to resiliency is too much difference among beliefs and world views with in a couple or family



Resiliency Framework

- Targets key processes:
 - Belief systems – making meaning of adversity, positive outlook, transcendence, and spirituality
 - Organizational patterns – flexibility, connectedness, social and economic resources
 - Communication processes – clarity, open emotional expression, collaborative problem solving



Resiliency Key Processes

- Tempering Mastery
- Reconstructing Identity
- Normalizing Ambivalence
- Revising Attachment
- Openings



Action Steps

- Have a therapeutic conversation by asking questions
 - What has changed in your life that maybe creating this stress?
 - How are you experiencing stress?
 - What is most stressful?
 - Do you feel torn about what you should do?
 - What things are doing now that are helpful to you at this time?



Action Steps cont'

- Label ambiguous loss directly with individuals and families
- Provide education about ambiguous loss as appropriate
- Identify the loss
- Identify consistencies in the lives of clients and family members



Action Steps cont'

- Encourage acceptance of difference among family members
- Facilitate clients' abilities to problem solve and move forward
- Provide continuity of care by encouraging individuals and families to share their ambiguous loss treatment planning with other services



The Place to Start

- Self-reflection
- We need to accept the fact that we can't always heal suffering
- The people we work with are less likely to tolerate ambiguity, if as health care professionals we are primarily focused towards fixing the problem



Self Study

- Who is in your psychological family?
- What ambiguous loss have you experienced?
- What type? Physical? Psychological? Both?
- What did it mean to you then? What does it mean now?