**Regaining Equilibrium: Understanding the Process of Sibling Adjustment to
Pediatric Acquired Brain Injury**

by

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“Suffering ceases to be suffering at the moment it finds a meaning,
such as the meaning of a sacrifice”

Viktor Frankl, 1905 – 1997.

ORIGINALITY OF THESIS

I hereby certify that this work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Samantha Bursnall

October 2003

Publications and Resources Arising from or Related to the Thesis

- Burnsnall, S. (2002). Assisting siblings when their brother or sister sustains acquired brain injury. *Surviving Acquired Brain Injury*, (pp. 119-132). Brisbane: Brain Injury Association of Queensland.
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ABSTRACT

This study developed a comprehensive framework for understanding the process of sibling adjustment to pediatric acquired brain injury (ABI). Grounded theory methodology was employed to inductively explore the issues siblings perceived to be their main concerns and how they managed these concerns. Fifty-three interviews were conducted recursively with twenty child and adolescent siblings of individuals with an ABI, four adult siblings of individuals with an ABI and four child and adolescent siblings of individuals with congenital disability. Observational and secondary data from hospital staff and parents were also analyzed. The framework was developed and verified through simultaneous data collection and analysis (Glaser, 1978; Strauss & Corbin, 1990).

The main issue of concern for siblings following their brother or sister's ABI was the loss of equilibrium in their lives. Losing equilibrium was defined by the concepts of *vulnerability* and *emotional turmoil*. Specifically, following ABI, siblings were confronted with the *vulnerability of their assumptive world*, which was influenced by their exposure to unforeseen circumstances, mortality, the enduring nature of their brother or sister's injury, and the perceived *vulnerability of their family unit*. In response to these losses, siblings experienced *emotional turmoil*, including acute anxiety, chronic worry, ambivalent emotions and disenfranchised grief. Losing equilibrium was an ongoing concern for siblings that threatened their sense of security, safety, predictability and control for many years post injury.

To manage these ongoing concerns, siblings employed a variety of interrelated strategies to regain equilibrium. These strategies were conceptualized by the concepts, *navigating* and *sacrificing*. The purpose of these strategies was to restore safety,

predictability and control in the siblings' environment. Navigating required siblings to negotiate the enduring disequilibrium in their lives, by *challenging new rules with old tools, withdrawal, trying and buying, merging the familiar and the unfamiliar* and *integrating*. Sacrificing required siblings to relinquish their needs and desires to regain equilibrium and was illustrated through the concepts, *surrogate parent, surrendering parental attention, emotional repression, and self-blame*. These *self-sacrificing* strategies appeared to influence siblings' long-term personal development. For instance, siblings believed that they became more *responsible, understanding, tolerant, and cautious* in everyday activities. The data indicated that these personal changes subsequently maintained siblings sacrificing behaviors. Although sacrificing strategies were employed by some siblings from the time of the ABI, most siblings mastered their loss of equilibrium through the navigating process. Like the non-finite nature of losing equilibrium, regaining equilibrium was an ongoing cyclical process.

Rather than focusing on adjustment outcomes only, the current study has extended previous research by providing a framework for understanding the process of sibling adjustment to ABI. This framework provides a set of integrated categories, concepts, hypotheses and propositions to inform future research and practice.

CHAPTER 1

INTRODUCTION

Acquired brain injury (ABI) following traumatic and non-traumatic insult is a leading cause of death and disability in children and adolescents (Appleton & Baldwin, 1998; Snow & Hooper, 1994). With advances in medical technology, many more children are surviving injuries that may otherwise have been fatal (Begali, 1992). Although statistics indicate that the incidence of an ABI in children is high, they do not convey the full magnitude of this tragedy because in reality the number of people who are affected is actually much larger. An injury to a child represents an injury to an entire family unit, including siblings (Gill & Wells, 2000; Kosciulek & Lustig, 1999).

Although sparse, research involving the impact of childhood ABI on family members has focused primarily on the parents of the injured child. Only a few studies have considered the experience of siblings following childhood ABI, and none have focused on siblings of children with an ABI in Australia. In contrast, a plethora of studies have focused on siblings of children with chronic illness or congenital disability. Despite this volume of research, however, the findings have been equivocal indicating that little is known about their needs and experiences.

For example, some researchers have suggested that the presence of a child with a disability or illness in the family may provide siblings with an opportunity for maturation or growth, empathy for the difficulties of others, maturity, tolerance for difference, enhanced social competence, compassion, responsibility and independence (Barbarin, et al., 1995; Chesler, Allswede & Barbarin, 1992; Crnic & Leconte, 1986; Havermans & Eiser, 1994; Horwitz & Kazak, 1990; Sargent et al., 1995). In contrast, other research has maintained that siblings of children with special needs experience

more stress, and have a higher risk of developing behavioral, social, psychological and emotional difficulties than children with no exposure to family disability or illness (Houtzager, Grootenhuys & Last, 1999; Lobato, Faust & Spirito, 1988; Williams, 1997). There is also evidence that childhood illness; death or disability may have lasting consequences for the siblings of these children (Fanos & Nickerson, 1991).

Little research has provided an appropriate framework from which interventions to address the needs of siblings of children with an ABI can be formed. It is likely, however, that the experience of having a brother or sister sustain an ABI would be extremely difficult. At present, this experience is inadequately recognized in the rehabilitation continuum. The research conducted to date on siblings of children with an ABI has been primarily concerned with maladjustment outcomes rather than the process of adjustment and a great deal of the research has been methodologically flawed.

Accordingly, the current study will address the limitations of previous research, by inductively exploring the impact of an ABI on siblings using the principles of grounded theory methodology¹. Research in this area is crucial in order to better understand the experiences and needs of siblings of children with an ABI and to inform health care systems of appropriate intervention strategies for these children.

¹ Grounded theory studies are sometimes presented in accordance with the nature in which they were conducted, which omits the use of a literature review prior to data collection and analysis. Grounded theory traditionalists (e.g. Glaser, 1998; Strauss & Corbin, 1998), however, acknowledge that many faculties within universities have requirements for dissertation write-ups and, therefore, accept the presentation of a grounded theory in a non-traditional sense.

To place this study and its significance in context, the present chapter will first present a descriptive review of the current research on childhood ABI. Second, the impact of childhood ABI on family members, including siblings, will be examined. Finally, current literature regarding siblings of children with special needs is also reviewed as it provides important methodological insights into future research considerations that are outlined in Chapter 2.

Pediatric Acquired Brain Injury

ABI refers to damage to the brain, not as a result of a degenerative or congenital condition, but caused by either traumatic or non-traumatic means and resulting in total or partial functional disability and/or psychosocial impairment (Appleton & Baldwin, 1998; Snow & Hooper, 1994). Traumatic brain injury (TBI) is insult to the brain caused by an external force, either as the result of a direct blow to the head or from acceleration-deceleration (e.g. through shaking of an infant or motor vehicle accident) (National Head Injury Foundation, 1985). TBI may be caused as a result of motor vehicle, motorcycle and bicycle accidents, as well as through falls, pedestrian accidents, non-accidental injuries (e.g. child abuse), sport-related injuries, assaults, and gun shot wounds (Frankowski, 1985; Ward, 1995).

ABI, however, may also result from non-traumatic means caused by disorders or illnesses such as meningitis, encephalitis, stroke, near-drowning accidents, asphyxiation, or through complications of surgical procedures, diabetes and metabolic or biochemical impairment (Appleton & Baldwin, 1998).

The majority of research on childhood ABI has focused on traumatic injury sequelae. However, outcomes for children with non-traumatic injury are equally

important (Appleton & Baldwin, 1998). Indeed, the problems, needs and methods of rehabilitation for children who have non-traumatic ABI and their families are similar to those who have suffered TBI (Baldwin, Nash, & Appleton, 1997; Miller, 1991).

Therefore, the term ABI will be used throughout this review unless a specific distinction has been made between TBI and non-traumatic ABI.

Incidence of ABI

Traumatic brain injury (TBI) is the most common cause of death and disability in childhood and adolescence, even superceding pediatric mortality rates from leukemia (Appleton, 1998; Snow & Hooper, 1994). Although little information about the incidence or prevalence of non-traumatic ABI exists, recent figures indicate that the prevalence may be as high as TBI (Appleton, 1998).

In Australia, ABI is a significant and widespread issue, in that the number of people who are severely affected is similar to the number of people with an intellectual disability and a quarter of those with a physical disability (Fortune & Wen, 1999). Although no recent figures are available about the prevalence of ABI in Queensland, a report by the Brain Injury Association of Queensland (Hearn, 2000) suggested that this state has the highest rate of ABI hospital admissions in Australia. The report suggested that in 1998 approximately 244,100 people in Queensland alone had experienced an ABI at some time in their lives and of these people, 63,400 experienced consequent disabilities that interfered with their daily living (Hearn, 2000). This high incidence of reported ABI was consistent with incidence and prevalence reports from other Western countries (National Head Injury Foundation, 1985; National Institute of Neurological Disorders and Stroke, 1989; Van Balen, Mulder, & Keyser, 1996).

Although Hearn's (2000) report did not specify the age of the ABI population, statistics in other western countries, such as Great Britain and the United States, suggest that approximately 150 to 220 per 100,000 children between birth and four years and approximately 550 per 100,000 children between fifteen and nineteen years sustain TBI (Annegers, 1983; Frankowski, Annegers & Whitman, 1985; Goldstein & Levin, 1987). Data from the National Institute of Health (NIH -1999) in the USA suggested that TBI occurs most often in young people between 15 and 24 years of age, and that males show twice the risk of sustaining TBI than females (Snow & Hooper, 1994). Although most pediatric TBI's are mild, about 10 to 15% are more severe in nature (Kirkwood et al., 2000).

Further, studies have reported that the highest incidence of TBI was observed in socio-cultural groups with the lowest median income (Kraus, 1987) and educational background (NIH, 1999). Higher incidence of TBI has also been found in rural as opposed to urban areas (NIH, 1999). Miller (1991) observed that although the incidence of non-traumatic ABI is likely to be as high as TBI, the population characteristics of these two groups may differ in that residence and status, for example, may be less implicated in its onset. Regardless of these possible differences, it is important to note that an ABI does not generally discriminate and may occur in people irrespective of their age, background and geographical location.

Evidence has also suggested that individuals who have sustained TBI are at increased risk of sustaining a second brain injury, perhaps due to the sequelae of the first TBI (Snow & Hooper, 1994). Annegers, Grabow, Kurland and Laws (1980) reported that this risk was twofold in children under 14 years, threefold in individuals

between 15 and 24 years of age and fivefold after age 25, with males being twice as likely to sustain a second TBI than females.

Data has also indicated that the incidence of childhood ABI is increasing due to a larger pediatric population, less parental supervision, and the increased use of motor vehicles and bicycles. In addition, the rate of reporting such incidents has likely contributed to this increase (Appleton, 1998).

Sequelae Of Pediatric ABI

Outcomes following an ABI can range from death and persistent vegetative states to mild physical, cognitive and/or psychosocial disabilities (Appleton & Baldwin, 1998; Ewing-Cobbs, Levin & Fletcher, 1998). Although the impact of an ABI on a child depends primarily on the severity of the injury (Ewing-Cobbs, Levin et al., 1998), even children who have sustained mild ABI often experience adjustment difficulties disproportionate to the expected consequences of that injury severity (Singer, 1996).

Childhood ABI differs from other childhood chronic illnesses and congenital disabilities because its impact is sudden and catastrophic (Wade, Drotar, Taylor & Stancin, 1995). ABI is also unique in that, despite the use of a single diagnostic term, people with an ABI represent a heterogeneous group with a wide range of physical, neurocognitive and psychosocial disabilities (Snow & Hooper, 1994; Ylvisaker, 1998). Children with an ABI, particularly children with TBI, may also differ to children with other chronic health impaired conditions in that these children are more likely to have pre-existing behavioral problems and come from families experiencing more

difficulties (Bijur, Haslum, & Golding, 1990). This difference has potential to impact on the sequelae following their injury.

No typical clinical presentation of an ABI exists because differences in the original injury can result in a wide range of outcomes (Cronin, 2001). Further, residual outcome appears to be the result of a complex interaction between pre-injury functioning, injury and post-injury supports and stressors (Ylvisaker, 1998). This is often complicated by the interaction between the multiple impairments that can be associated with an ABI (Ylvisaker, 1998).

The impact of an ABI can range from pronounced and chronic changes to more subtle changes that are apparent only on formal neuropsychological examinations (Ewing-Cobbs, Levin et al., 1998). Indeed, an ABI is often referred to as the “hidden disability” because an individual’s physical recovery from an ABI may appear “normal” but masks underlying cognitive or emotional deficits. Adding to the hidden nature of an ABI is the fact that an ABI in children can disrupt functions that are developing or that have not yet begun to develop (Mateer, Kerns & Eso, 1997).

Thus, children with an ABI who appear to have recovered from their injuries, may, over time, demonstrate deterioration in cognitive, behavioral, social and emotional functioning, weeks, months or years post-injury (Beers, 1992; Grattan & Eslinger, 1991; Mateer & Williams, 1991). This process of “growing into a deficit” (Mateer, Kerns & Eso, 1997, p. 155) may be exacerbated by increased academic and social demands that are placed on children with an ABI as they develop and mature, therefore, placing pressure on their already compromised learning abilities.

Alternatively, new circumstances may require abilities that are dependent on damaged brain regions that have failed to develop (Barth, Gideon, Sciara, Hulsey, & Anchor,

1986; Ylvisaker & Szekeres, 1998), thus exposing deficits that had previously not been evident.

Despite this extreme variability among individuals with an ABI, there are common themes that unite the population. Specifically, these children are likely to experience lengthy hospital stays, numerous outpatient hospital visits, on-going rehabilitation and re-integration into their community with new limitations. Their injury and subsequent disability are acquired after a period of normal development, resulting in losses in ability, anticipated accomplishments, activities and friends. The injury also usually results in a complex range of physical, cognitive, psychiatric, psychosocial and behavioral consequences that are permanent and enduring (Ylvisaker, 1998). In order to understand the impact that an ABI may have on children, their parents and siblings, a brief review of these possible consequences following an ABI is useful. This review is by no means exhaustive, and no attempt is made to examine the many mediating and associated variables present in the research. Nonetheless, the enormous impact that an ABI may have on a young person and their family is evidenced clearly.

Motor And Sensory Sequelae of ABI

Although research concerning motor and sensory sequelae following an ABI has received little attention (Roth, 2001), existing research shows that an ABI can result in varying degrees of motor deficit, ranging from mild impairment of fine movements to paralysis causing a complete loss of functional ability (Begali, 1992). Common motor problems following childhood ABI include spasticity, ataxia, contractures, altered joint mobility or stability, atrophy, paralysis and speech

disturbances, as well as hemiplegia, hemiparesis, hypotonicity, rigidity, tremors, apraxia, and dysarthria (Begali, 1992, Cronin, 2001), sometimes causing children to become totally physically dependent. Research indicates that even children with mild or moderate TBI without motor impairments may experience reduced functional performance (Coster, Haley & Baryza, 1994).

Common somatosensory perceptual difficulties following an ABI include impaired postural awareness and orientation, sensation impairments, tactile sensory dysfunction and spacial disorientation (Blaskey & Jennings, 1999; Carney & Gerring, 1990). In addition, sensory system impairments, such as, audiological and visual system impairments, as well as visual perceptual and visual acuity impairments may develop as a result of an ABI (DiScala, Osberg & Savage, 1997). Even mild ABI may result in varying degrees of motor and sensory impairment leading to deficits in reading and writing (Begali, 1992), that ultimately impact on the child's re-entry into the school and social environment (Kinsella et al., 1997).

Epilepsy may also arise as a secondary complication following an ABI (Begali, 1992; Nash, Appleton, Rowland, Saltmarsh, & Sellars, 1997). This can occur years after ABI onset, although children are most likely to develop epilepsy in the immediate and early post-injury period (Begali, 1992).

Cognitive Sequelae of ABI

While most children with motor impairments following an ABI are reported to have a good prognosis (Blaskey & Jennings, 1999; Winkler, 1995), cognitive, intellectual and academic problems appear to be more persistent (Cronin, 2001; Knights, Ivan & Ventrueyra, 1991). Although cognitive deficits differ across

individuals, the most common and persistent functions likely to be disrupted include attention, concentration, judgment and impulse control (Anderson, Fenwick, Manly & Robertson, 1998), memory, intellectual, language and executive functions, information processing speed and abstract reasoning (Begali, 1992; Guthrie, Mast, Richards, McQuaid & Pavlakis, 1989; Porr, 1999; Snow & Hooper, 1994; Yeates, 2000).

A review of the literature suggests that intelligence and academic performance declines in children following TBI. Although most studies report that deficits in intellectual functioning are most evident in people with severe ABI, a study conducted by Pinkston, Santa-Maria, and Davis (2000) suggested that intellectual and cognitive deficits can persist for up to five years post-injury, even in cases of moderate severity. Further, a two and a quarter year prospective study conducted by Chadwick, Rutter, Brown, Shaffer and Traub, (1981) found that the cognitive performance of children with mild injury was worse when compared to a control group at all time points. Similarly, research assessing IQ from one to five years post-injury has suggested that only partial recovery of intellectual abilities may be possible in children with severe TBI (Mayes, Pelco & Campbell, 1989).

Children and adults with an ABI show similar types of cognitive deficits. However, the long-term effects of these deficits, combined with the active developmental process in children, produces different patterns of recovery in children (Ewing-Cobbs, Levin et al., 1998; Verger, et al., 2000). In contrast to the traditional belief that children recover more quickly than adults, research has suggested that children show persistent cognitive and behavioral deficits despite resuming daily routines, such as school (Fay, et al., 1994; Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990). Indeed, comparing children and adolescents with head injury, Levin,

Culhane & Mendelsohn, (1993), found that cognitive impairment was more consistently present in children who were injured at a younger age. Evidence also suggests that older children and adults have a better recovery than preschool-aged children following TBI (Lazar & Menaldino, 1995; Verger, et al., 2000), particularly with regard to language (Varghi-Khadem, O’Gorham & Watter, 1985).

Memory impairments are also extremely frequent and disruptive in children following an ABI (Dalby & Obrzut, 1991; Max et al., 1999). These impairments hinder the ability to recall previously learned information or experiences, to remember recent events or to acquire new information, behaviors and skills. Although memory problems are often noticed soon after the onset, the full impact is often only realized many years post injury (Mateer et al., 1997).

Deficits in concentration and attention are other observed cognitive sequelae following an ABI in children and adults (Beers, 1992; Kaufmann et al., 1993) often contributing to significant disability following an ABI (Klonoff, Clark & Klonoff, 1993). Children with an ABI may experience an inability to concentrate for long time frames, have slowed speed of information processing and poor response time, poor working memory, difficulties with cognitive and behavioral flexibility and dual task processing, all of which interfere with academic performance (Case, 1992; Mateer et al., 1997).

Executive functioning is also commonly impacted following an ABI. Given that the executive system is associated with the large prefrontal areas of the brain responsible for formulating, constructing, and executing plans (Ylvisaker & Szekeres, 1998), impairment to this area may result in a child’s inability to self-manage, self-regulate and self-control. Such impairment may also impact on a child’s ability to

socially interact, impeding their ability to follow social rules, roles and routine (Ylvisaker & Szekeres, 1998), and may present difficulties with age-appropriate behaviors, family and peer relationships (Savage & Wolcott, 1994). Clearly, impaired cognitive functioning can have a detrimental and enduring impact on young people following an ABI (Fay et al., 1994).

Psychosocial and Behavioral Sequelae of ABI

In addition to impaired cognitive functioning, other prevalent and enduring problems following an ABI are social maladjustment and poor quality of life related to psychiatric, psychosocial and behavioral sequelae (Cattelani, Lombardi, Brianti, & Mazzucchi, 1998). The risk for psychosocial and behavioral complication is substantially increased following an ABI (Ewing-Cobbs et al., 1998; Luiselli, et al., 2000). These problems are likely to be more enduring and disturbing to the child and their family than physical sequelae (McKinlay, Brooks, Bond, Martinage & Marshall, 1981), and often manifest as problems in a child's psychiatric and emotional functioning, personality, behavior and social interaction.

Psychiatric disorders have been shown to be three times more prevalent in children with severe ABI when compared to controls (Brown, Chadwick, Shaffer, Rutter, & Traub, 1981; Rutter, 1981). Bloom et al. (2001) assessed lifetime and current psychiatric disorders in 46 children and adolescents at least one year following TBI. The findings from this study revealed that attention-deficit/ hyperactivity disorder (ADHD) and depressive disorders were the most common diagnoses. Also identified were a wide variety of psychiatric disorders, 74% of which persisted in 48% of the children with TBI, with internalizing disorders more likely to resolve than

externalizing disorders. The high rate of psychiatric disorder in children and adolescents found in this study (at least one year post injury) were consistent with other prospective (Brown, et al., 1981; Max et al., 1997 a-b) and retrospective studies (Lehmkuhl & Thoma, 1990; Max et al 1998 a-b).

Similarly, Kirkwood et al. (2000) found that although children between ages 6 and 12 did not demonstrate clinically significant levels of depression following TBI at 6 and 12 month follow-up, they seemed to be at increased risk of exhibiting depressive symptoms over time when compared to children following orthopedic injuries. Indeed, it has been suggested that the neuropathology of ABI (e.g. insult to brain regions implicated in emotional regulations) is likely to place a child at increased risk of emotional problems, such as depression (Ownsworth & Oei, 1998). Other consequences often associated with ABI, such as, declined academic performance, loss of peer relationships, and loss of independence may also implicate emotional disorders in children following ABI (Kirkwood et al., 2000).

Another notable change thought to be directly related to the physiological effects of TBI is personality change (Max, Robertson & Lansing, 2001). Personality change (PC) is “characterized by persistent personality disturbance” and appears as a formal diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV (American Psychiatric Association, 1994; Max, Robertson & Lansing, 2001, p. 161).

Characteristically, PC causes clinically significant distress and impairment in social, occupational, and or other important areas of a child’s functioning (Max et al., 2001). Max et al. (2000) investigated the nature of PC following childhood ABI and found that approximately 40% of children with severe TBI displayed persistent PC for up to two years after their injury. A history of temporary PC was evident in an

additional 20% of the children in the study, however, only 5% of children with mild/moderate TBI experienced temporary PC lasting less than three months. In a follow-up study, Max and his colleagues described the symptomatology associated with a diagnosis of PC, which often overlapped with symptoms associated with ADHD, ODD, mania and hypermania (Max et al., 2001). The findings showed that of the 59% of children with severe TBI who displayed PC, 49% were characterized by the labile subtype (e.g. “marked shifts from normal mood to irritability”); 38% by the aggressive and disinhibited subtype (e.g. “disinhibited vocalization/verbalization”); 14% by the apathetic subtype (e.g. lack of interest in life); and 5% by the paranoid subtype (p.2-3). Another symptom associated with PC was perseveration (e.g. constant repetition of statements or information). Over half the children in Max et al.’s study were characterized by more than one subtype of PC, with most having poor insight into their condition (Max et al., 2001).

An increased rate of behavioral problems can also result from an ABI, even if a child has no previous history of behavioral or developmental disturbance (Kehle, Clark & Jenson, 1997). In fact, Michaud, Rivara, Jaffe, Fay, and Dailey (1993) suggested that children and adolescents with TBI are three times more likely to develop behavior disturbance than the general population. Common behavioral problems to result from an ABI include a loss of self-control, a loss of awareness of self and others, hyperactivity, and problems with sexuality, grooming, family relationships and age-appropriate behavior (Basson et al., 1991; Knights et al., 1991; Savage & Wolcott, 1994). A study conducted by Andrews, Rose and Johnson (1998), found significantly higher levels of loneliness, maladaptive behavior and aggressive/antisocial behavior,

and lower levels of self-esteem and adaptive behavior in children aged between 6 and 17 years following TBI.

Socially, children with an ABI may become apathetic, easily angered or withdrawn (Barin, Hanchett, Jacob, & Scott, 1985) and their peer relationships are often damaged (Sherwin & O'Shanick, 1998). In fact, Willer, Allen, Durnan and Ferry (1990) found that one of the primary problems for young men with TBI was retaining and making friendships. This finding is not surprising given the common behavioral complications following an ABI, such as, socially disinhibited behavior, reduced social skills, poor impulse and temper control, loss of insight and inappropriateness (Brown et al., 1981; Knights et al., 1991). These deficits are often misunderstood and not tolerated by peers. For adolescents, ABI may exacerbate the emotional and behavioral problems that are often associated with this time period and interfere with the achievement of healthy autonomy (Bragg, Klockars, & Berninger, 1992). Indeed, Bragg and colleagues (1992) found that adolescent males who had sustained mild to moderate TBI (ages 14 to 18 years) show significantly more maladaptive behaviors and displayed them more frequently than adolescent males in a comparison group.

Sadly, once behavioral problems are present, they appear to persist or worsen over time (Kehle et al., 1997). For example, in one early study, children with severe TBI showed 300% increase in behavior problems over a two year period (Brown et al., 1981). Similarly, in a later study conducted by Unsworth, Godfrey, Bishara and Sanders (1998), parent and observational reports indicated greater levels of behavioral and mood disturbance in children with TBI than in children with orthopedic injuries up to five years post-injury. Findings from other long-term follow-up studies further suggest that post-injury behavior and scholastic problems continue over time, despite

partial recovery in cognitive functions (Fay et al., 1994; Kinsella, Ong, Murtagh, Prior, & Sawyer, 1999).

Rehabilitation and Service Provision Regarding ABI Sequelae

Not surprisingly, the chronic sequelae that some children and adolescents exhibit following an ABI, often requires continuous monitoring and intervention in the community setting (Cronin, 2001). In fact, Lazar and Menaldino (1995) advised that young people with TBI require continuous support in their transition from school “beyond the point of apparent cognitive recovery” (p. 59). Unfortunately, however, children and adolescents are seldom referred for rehabilitation services, particularly regarding psychosocial and behavioral sequelae (Cronin, 2001; Serio, Kreutzer & Gervasio, 1995).

For example, DiScala et al., (1997) examined the support provided to a group of children and adolescents following hospitalization for TBI. They found that of the 27% of children who leave hospital with functional limitations in vision, hearing, speech, dressing, bathing, walking, cognition or behavior, 75% were discharged home, with only 1.8% referred for special education and community-based services. Further, although psychosocial and behavioral sequelae are often present in children with mild and moderate brain injury, most of these children are discharged to their home communities, often with little follow-up or support services (Arroyos-Jurado, Paulsen, Merrell, Lindgren & Max, 2000; DiScala, Osberg, Gans, Chin & Grant, 1991). Instead, responsibility for a child’s rehabilitation most often falls on the family (Gan & Schuller, 2002).

Families, however, lack the formal training, information and preparation necessary for managing the many changes and stressors presented by a child's ABI (Cronin, 2001), placing enormous strain on the family and challenging cohesive family functioning. The toll of caring for a family member with an ABI is significant, with many families experiencing emotional distress (Perlesz, Kinsella & Crowe, 2000). Indeed, studies documenting the impact of a child's ABI on family members indicate that families are often more distressed than the person with the injury (Brooks, 1991). The family's ability to cope and adjust to this impact, however, is crucial given that the family environment appears to be significant in either helping or hindering the child's successful rehabilitation and community re-entry (Kaplan, 1991; Kinsella et al., 1999; Martin, 1990; Taylor et al., 2002; Wade et al., 1995).

For instance, although a range of variables have been shown to mediate the outcome of childhood ABI, a recent study conducted by Taylor et al. (2002), suggested that post-injury progress may be influenced by the family environment. Indeed, Kirkwood et al. (2000) found that TBI increased the risk of depressive symptoms in children, especially among those from socially disadvantaged families, while Taylor et al. (2002) found that coming from a socially disadvantaged family predicted adverse behavioral sequelae in children. Family psychiatric history, family dysfunction, and marital discord have also been associated with TBI outcome in children (Barry & Clark, 1992; Kinsella et al., 1999; Taylor et al., 2002; Wade, Taylor, Drotar, Stancin & Yeates, 1996).

An understanding of how an ABI affects families seems crucial to inform interventions that can assist families to cope. This, in turn, may result in better outcomes for the children. Indeed, studies have shown that family support, particularly

from cohesive, intact, and functional family systems, results in better rehabilitation outcomes and successful employment for adults with an ABI, when compared to those without intact family support (Kaplan, 1991; Kaplan & Questad, 1980).

Summary

The literature demonstrates that the impact of an ABI on children and adolescents can be devastating and far-reaching. Many children experience a loss of functional abilities and psychiatric and behavioral deficits that impact on their daily lives and relationships. Importantly, these deficits often continue into adulthood and may be influenced by family adjustment. The implications of these substantial long-term outcomes, however, are not limited to the individual with an ABI. Responsibility for the rehabilitation and life-long support of these young people most often falls on family members (Gan & Schuller, 2002) resulting in implications for the entire family system (Kosciulek, 1994).

The bi-directional influence of a child's ABI on family members and visa versa highlights the notion of interdependence and mutual influence as described by family systems theory (Whitchurch & Constantine, 1993). Although much has been done to increase understanding of the impact of an ABI on children and adolescents, only in the last decade or two has there been widespread recognition that an equal emphasis must be given to the impact of pediatric ABI on the family (Martin, 1990). According to Kosciulek, McCubbin and McCubbin (1993) family members are at increased risk for emotional and social difficulties and, thus, require understanding and assistance as much as those impacted by an ABI.

The Impact of Pediatric ABI on the Family: A Family Systems Perspective

According to family systems theory, the family is viewed as an holistic system (Whitchurch & Constantine, 1993), constituting many sub-systems (i.e., the parent sub-system, sibling sub-system) and existing within a suprasystem of the community. Family systems theory asserts that the family system is interdependent and mutually influential (Maitz & Sachs, 1995). Thus, change in one family member (e.g. due to an ABI) is processed by all members, representing change for the entire family unit (Whitchurch & Constantine, 1993).

The impact of an ABI may be considered a second-order change in that it is a major, higher level of change that results in the alteration of the entire family system (Whitchurch & Constantine, 1993). This kind of change is considered dramatic and enduring, requiring a reorganization of the system into new transactional patterns (Montgomery & Fewer, 1988). Although research examining the impact of pediatric ABI on the family is sparse, available evidence indicates that, consistent with family systems theory, the initial impact and ongoing sequelae of ABI results in substantial change and distress for the family (Ergh, Rapport, Coleman & Hanks, 2002; Wade, Taylor, Drotar, Stancin & Yeates, 1998).

For instance, literature regarding the impact of ABI on families consistently reports that families experience a range of psychological distress, including, anger, guilt, denial, depression, grief, and psychosomatic disorders in response to their family member's ABI (Florian & Katz, 1991; Florian, Katz, & Lahav, 1989; Kreutzer, Marwotz & Kepler, 1992; Lezak, 1988, Livingstone & Brooks, 1988; Perlesz, Kinsella & Crowe, 1999). Hall et al. (1994) found that withdrawal from social contacts and financial strain also created stress for family members following TBI. Indeed, Ergh et

al. (2002) suggested that although social support minimized carer distress and was the strongest predictor of family functioning, many social support systems diminish for children and their families following an ABI (Thomsen, 1984). Further, many family members are required to give up work in order to become full-time carers following their relative's TBI. Jacobs (1988) reported that 28% of families exhausted all or most of their financial resources, and 24% experienced mild to moderate financial drain following TBI. Inadequate support, preparation and rehabilitation have also demonstrated an impact on the family system's ability to cope with the long-term effects of TBI. (Resnick, 1993).

In general, evidence suggests that these families experience disruption to their routine and family dynamics, increased stress, poorer family functioning, organizational difficulties and changes in family socialization patterns for many years following the onset of ABI. They may also experience increased psychological distress in the primary caregiver, accompanying marital tensions and financial strain (Peters, Stambrook, Moore & Essess, 1990; Waaland & Raines, 1991; Wade, Taylor, Drotar, Stancin & Yeates, 1997).

Impact of ABI on Family Burden and Stress

The onset of an ABI is sudden and unexpected. The experience is "marked by the specter of death" (Foster & Carlson-Green, 1993, p. 173) and uncertainty about the ABI prognosis (Appleton & Baldwin, 1998; Martin, 1990). Given these conditions, change in the family system is likely to occur from the onset. In the first weeks after the injury, Wade et al. (1996) found that compared to parents of children with orthopedic injuries, parents of children with severe TBI reported significantly greater

acute injury–related stress and burden. This injury-related stress and burden was associated with concerns regarding medical management, changes in the injured child’s behavior, family concerns, and disruption in family routines (Wade et al., 1998). The parents of children with TBI also reported significantly higher levels of psychological symptoms during the initial few weeks following TBI onset. Wade, Taylor, Drotar, Stancin & Yeates (2002), suggested that “family difficulties after severe TBI peak during the initial months after injury...” (p. 101).

Although the initial onset of an ABI is often traumatic and stressful, research shows that the effect of an ABI on the family is likely to vary across time (Lezak, 1987; Wade et al., 1998). Families may experience different stresses and demands over the course of the child’s recovery process (Rivara, 1994; Wade et al., 1997) with the stresses and demands associated with an acute hospitalization likely to be different to those arising from chronic neurocognitive, psychosocial, and behavioral sequelae (Wade et al., 1996). For instance, in a follow-up study, Wade et al. (1998) found that at the time of hospital discharge, injury-related burden was greatest for families with children who had sustained both TBI (moderate and severe) and orthopedic injuries. However, by six months post injury, burden in families of children with orthopedic injuries significantly fell. By 12 months post injury, families of children with TBI reported more stress than those in the orthopedic group (Wade et al., 1998). Despite a decline in injury-related stress and burden over time for all groups, the families of children with severe TBI continued to experience more burden at four year follow-up (Wade et al., 2002). Clearly, these findings suggest that following discharge from hospital, the enduring neurocognitive, psychosocial and behavioral sequelae evident in

children with TBI may act as continued sources of stress and burden for family members (Wade et al., 1998).

Indeed, Sokol et al. (1996) found that almost 44% of parents of children with TBI were significantly stressed 1-5 years post injury (over twice that expected in the general population), and attributed their stress to difficulties in accepting their injured child's behavior, distractibility and demanding traits. Similarly, in a study conducted by Perrott, Taylor and Montes (1991) parents reported that their children with an ABI were significantly more demanding and distractible, and caused higher levels of stress than their siblings. These findings are consistent with longitudinal research on the impact of adult TBI on family, which shows that stress and burden regarding TBI sequelae persists over time (Brooks, Campsie, Symington, Beattie & McKinlay., 1986; Linn, Allen, & Willer, 1994).

Impact of ABI on Family Functioning

Rivara et al. (1992; 1996) prospectively examined the long-term impact of childhood TBI (mild, moderate, and severe) on family functioning 3, 12 and 36 months post injury in children aged 6 to 15 years. As indicated by interviewer ratings pre-injury to post-injury, deterioration in marital, peer and family relationships, as well as, global family functioning was observed in the families whose children suffered severe TBI. The deterioration in family functioning was also observed at 12 (Rivara, et al., 1992) and 36 month follow-up (Rivara et al., 1996).

Similarly, Bragg et al. (1992) found that compared to a control group, families of adolescent males with TBI, sustained at least two years prior, scored lower on six of seven sub-scales on the Family Assessment Device (including problem-solving,

communication, role dimension, affective responsiveness, active involvement and general functioning), indicating that these families perceived their entire family system to have been disrupted by TBI.

In contrast to these findings, Wade and her colleagues (2002) found that family difficulties (as indicated by parental reports) reported at six months post-injury actually returned to levels comparable to families of children with orthopedic injury by one-year follow-up. However, although not significant, by four-year follow-up, there was again a trend for the families in the TBI group to report more family dysfunction than the orthopedic group. Lezak (1986) suggested that these patterns of familial response may be due to the child's initial dramatic recovery that plateaus over time, leaving the family aware that the child's deficits and losses are permanent. Indeed, studies reporting on family distress and dysfunction following adult TBI, suggest that stresses may in fact intensify rather than reduce over time (Brooks, 1991; McKinlay et al., 1981).

Kosciulek et al., (1993), however, proposed that family adaptation to an ABI should be viewed as a dynamic and ongoing process that is influenced by many factors over time. These authors suggested that following an ABI, families strive to achieve harmony, coherence and balance. The level to which this harmony is achieved is influenced by the accumulation of demands on the family system over time (e.g., demands relating to an ABI, demands resulting from past, present and evolving life transitions), as well as, the family's typology, strengths, resources, supports, situational appraisal and adaptive coping and management strategies. This research, therefore, implies that the impact of a child's ABI on the family may be complex and enduring, further necessitating the need to understand the experience of siblings.

Summary

Many families show enormous resilience following an ABI, with no apparent long-term negative effects (Wade et al., 1997). However, a great deal of evidence suggests that there are negative consequences for families. Despite the value of the family systems approach most studies have focused on individual caregivers' psychological outcome (usually parents and spouses), often referring to the results as indicators of 'family functioning' (Gan & Schuller, 2002). From a family systems perspective, however, it seems likely that changes in a child and subsequent stress in parents will impact strongly on the siblings of these children.

Only a small amount of research has explicitly examined the impact of an ABI on siblings, and preliminary observations suggest that it may be considerable. Some studies have used siblings as a control group (Perrott, et al., 1991) or included them as a data source when assessing family functioning (Wade et al., 1998; 2002). Combining responses from different family members to obtain an estimate of family functioning, however, may obscure important differences, particularly in relation to the interactions with specific dyads or sub-systems (Perlesz et al., 1999; Wade et al., 1995). Family systems theory recognizes that sub-systems within the family system have their own interdependence and mutual influence among their members, with their own relationship boundaries (Whitchurch & Constantine, 1993). However, one important family sub-system that is often overlooked is that of the sibling sub-system. Understanding how the sibling sub-system may have been altered by an ABI is essential so that clinicians can better target their interventions toward the entire family unit (Gan & Schuller, 2002).

Siblings: An Important Family Sub-System

Early assumptions that parents and peers were the primary influences on child and adolescent development, and that the sibling relationship was inconsequential, were challenged by the emergence of family systems theory (Cicirelli, 1995). As described earlier, family systems theory recognizes the sibling relationship as a significant sub-system, part of a larger interdependent family system with unique qualities and influences on individual development. Indeed, the sibling relationship has the potential for a longer duration than most other relationships (Cicirelli, 1991). Siblings share between 33% and 66% of their genes (Scarr & Gracek, 1982), making this ascribed relationship one which many individuals make a life-time commitment to maintain (Cicirelli, 1991). Because of the length and intensity of this relationship, siblings greatly influence one another's development, behavior, personality, attitude and identity, independent of their genes or parental influences (Cicirelli, 1995). In addition to its long duration, the sibling relationship is relatively egalitarian, further distinguishing it from other family sub-systems (Cicirelli, 1991). The sibling subsystem is never static but evolves over time as members of the family system are born, die, or change their circumstances (Bank & Kahn, 1997).

According to Bank and Kahn (1997), the relationship has "a distinctive emotional, passionate, painful and solacing power which shapes the story of who we are and who we become" (p. XV). The emotional bond that exists between siblings is often characterized by complex dynamics, such as love, hate, jealousy, rivalry, companionship, solidarity, loyalty, competition, and affection (Bank & Kahn, 1997).

If siblings act as referents in the development of their brother or sisters' identity, particularly during adolescence, the impact of an ABI in a sibling is likely to

be significant. Indeed, researchers examining the impact of pediatric chronic illness on siblings concluded that “in some domains, siblings experience even more distress than the patients ... and that the emotional needs of siblings are least adequately met of all family members” (Houtzager, Grootenhuis & Last, 1999, p. 303). Florian and Katz (1991) considered siblings to be “additional victims of TBI” (p. 273) who were in need of greater attention in rehabilitation programs.

The Impact of ABI on Siblings

Although it has been recognized for a few decades that an ABI is a “family affair” (Lezak, 1988), little research has examined the impact on siblings (Kreutzer et al., 1992; Perlesz et al., 1999). In a critical review of thirty-seven family outcome studies following TBI, Australian researchers Perlesz et al. (1999) revealed that most focused on the psychosocial outcome for parents and spouses, with only a small number of studies focusing on siblings of children with TBI. The studies featuring siblings were predominantly North American. These studies, nonetheless, suggested that the sudden changes caused by an ABI may be particularly stressful for siblings (Orsillo, McCaffrey, & Fisher, 1993), with some observations that the relationship between parents and non-injured siblings may change (Waaland & Kreutzer, 1988; Waaland & Raines, 1991).

Orsillo et al. (1993) conducted one of the first empirical investigations of the impact of TBI on a convenience sample of 13 siblings (8 females and 5 males) who were between seven and twenty-eight years of age when their brother or sister sustained TBI. The siblings completed the McMaster Family Assessment Device (FAD), the Problem Solving Inventory (PSI), the Dysfunctional Attitude Scale (DAS),

the Rational Behavior Inventory (RBI), the Attributional Style Questionnaire (ASQ), the Revised Ways of Coping Checklist (WCCL), and the Brief Symptom Inventory (BSI). This study showed that “siblings experienced significant levels of psychological distress as long as five years post injury” (p. 110), with 83% of the sample meeting diagnostic criteria on the BSI (Orsillo et al., 1993). Siblings perceived themselves to have ineffectual coping and poor problem solving-skills. They reported a greater number of dysfunctional attitudes and higher levels of family dysfunction than normative data. This study further suggested that siblings’ cognitive and behavioral styles may contribute to their level of psychological distress, and that identifying their cognitive-behavioral style may help to predict adjustment difficulties. Interpretation of this data is limited, however, by sampling bias, lack of power, and the lack of a control group.

Using a larger sample size, Peretti and Abderholden (1995) interviewed forty siblings of children with congenital and acquired brain damage who were between 4 and 11 years of age. The interviews focused on the effect of imputed or implied loss of parental attention due to the needs of the child with brain damage. Their study found that most siblings reported feelings of anger (87.5%), jealousy (77%), rejection (72%), depression (64.5%) and loneliness (60.4%) in response to their perceived loss of parental attention. However, as the sample was recruited from previous clients of psychotherapy referred due to intense sibling rivalry, these findings are misleading.

In contrast to these findings, a more methodologically sound cross-sectional study conducted by McMahon, Noll, Michaud and Johnson (2001) found no differences between siblings of children with an ABI and controls. Although sample size was small, the study systematically assessed the psychological functioning of

twelve siblings between 8 and 17 years of age (mean = 13.3 years) in the first 18 months after their brother or sister sustained severe TBI. A control group (mean = 13.1 years) was randomly selected from the siblings' classmates. All siblings completed measures of self-perception and depression, while their teachers and primary caregivers completed the Child Behavior Checklist. Although no statistically significant differences were found between siblings and their classmates, a poorer functional outcome at discharge in the child with TBI significantly correlated with poor self-concept and symptoms of depression in siblings. Although causality could not be determined, McMahon et al. (2001) speculated that the adjustment difficulties in siblings may be associated with factors such as increased parental stress, decreased parental time and attention given to siblings, increased responsibilities for siblings and role changes in the siblings' relationships.

Studies conducted by Willer et al. (1990) and Gill and Wells (2000) have provided support for these assumptions. For instance, Willer et al. (1990) identified common problems and useful coping strategies in siblings of young males who had sustained TBI. Siblings (five sisters and two brothers, with a mean age of 17 years) participated in a voluntary family retreat weekend. Apart from one sibling, all siblings were older than their brother with TBI. Using the nominal group technique, qualitative data derived from group discussion among the seven siblings revealed that non-injured siblings rated family distress and concern for their injured brothers' future as the most significant problem affecting them following the TBI. They also described significant changes to their family lifestyle, including increased personal responsibilities and barriers to autonomy for their injured brothers. Some siblings were interviewed up to 18 years post injury, providing further support that an ABI continues to impact on

family members for many years post-injury. Siblings identified the use of education, communication and suppression of their feelings and frustrations as their primary means of coping with these problems (Willer et al., 1990).

Using a less structured individual interview technique, Gill and Wells (2000) found that TBI may have long-term consequences for siblings. These researchers examined the experience of eight siblings of individuals with TBI between three and fourteen years post-injury. The siblings ranged from 14 to 30 years of age and lived with their brother or sister with TBI at the time of the study. The interview data revealed a common overarching theme that emerged from the interviews. Specifically, siblings reported that their lives were “forever different”, particularly in relation to their expectations about the future. They perceived their peers with “normally” developing siblings to have fewer responsibilities and more opportunities. Siblings reported that their daily life rhythm changed following their sibling’s TBI in that they assumed many task-oriented (e.g., household chores) and cognitive-emotional responsibilities (e.g., assisting their injured sibling with problem-solving tasks or social interactions) in order to maintain a sense of harmony following discharge from hospital. All participants reported changes in their relationships with family and friends, but their views were polarized in terms of their relationships with the sibling with TBI. Half the participants described feeling closer to their brother or sister with TBI whereas the other half reported a loss of closeness. Their roles within the sibling relationship were also redefined in that younger siblings took on the responsibility usually expected of older siblings. Some siblings reported spending less time with friends, while others reported spending more time with friends, sometimes including their injured sibling in their friendship circles.

Finally, siblings reported experiencing changes in the way they perceived themselves and their priorities, which they attributed to their increased responsibility and the increased self-awareness gained from experiencing such a significant life event. These changes in priorities included a wish to help other people, focus on work rather than friends, and place family above anything else. Gill and Wells (2000) interpreted their findings using family systems theory.

Although an interesting finding, this study was descriptive, leaving questions about the underlying processes of sibling adjustment following an ABI. In particular it failed to examine the processes for coping with and managing the experience of having a sibling with an ABI. The study lacked depth of analysis and interpretation in relation to how and under what conditions problems for siblings arose and were resolved. Further, the rigor in which this method was undertaken was not made explicit, calling into question the credibility of the findings (Sandelowski, 1986).

Impact of Childhood Illness and Disability on Siblings

The more abundant literature examining the impact of illness and congenital disability on siblings provides no further clarity in terms of extrapolating some of the difficulties likely to be experienced by siblings of children with an ABI. These studies are also equivocal and marked by contradictory and divergent interpretations making it difficult to draw consistent conclusions about the impact of disability or illness on siblings (Bluebond-Langner, 1996).

For instance, in a recent review of studies undertaken on siblings of children with pediatric chronic illness (including siblings of children with various congenital disabilities), Williams (1997) found that “the majority of the reviewed studies reported

an increased risk in siblings which were manifested in various ways” (p. 317-318). These studies (approximately 60% of those reviewed) reported that siblings of children with chronic illnesses and disabilities showed increased risk of psychological, emotional and social difficulties (Breslau & Prabucki, 1987; Cadman, Boyle & Offord, 1988; McHale & Gamble, 1989); internalizing and externalizing behavior problems (Cohen, Freidrich, Jaworski, Copeland & Pendergrass 1995); multiple behavior problems (Lobato, Barbour, Hall & Miller, 1987; Sahler & Carpenter, 1987); decreased social and school activities; school adjustment problems (Tew & Laurence, 1973; Williams, Lorenzo, & Borja, 1993); and somatic complaints (e.g. Sahler & Carpenter, 1987; Walker, 1988). Further, siblings reported feelings of isolation, loneliness, anxiety, lowered self-esteem, loss of parental attention, rejection, fear, guilt, frustration, anger and increased responsibility (Bendor, 1990; Chesler et al., 1992; Kramer, 1984; Packman et al., 1997; Zeltzer et al., 1996).

Despite the suggestion that siblings may be at risk of emotional, social, behavioral and psychological problems, 30% of studies contained in Williams’ (1997) review reported no risk to siblings and 10% reported both positive and negative outcomes (Williams, 1997). Other researchers have also suggested that the presence of a child with a disability or illness does not necessarily indicate that siblings will develop psychological problems (Bischoff & Tingstrom, 1991). Instead, the presence of a child with a disability may provide some siblings with the opportunity for personal growth, empathy for others, maturity and tolerance (Burton, 1987; Crnic & Leconte, 1986; McHale, Sloan & Simeonsson, 1986). In support for this suggestion, Horwitz and Kazak (1990) found lower levels of behavior problems and higher levels of emotional growth in preschool siblings of children with cancer than in control children.

Grossman (1972) found that college students who had siblings with disabilities were more tolerant, more aware of prejudice and more certain about their goals and aspirations than college students without siblings with disabilities. In addition, Ferrari (1984) found that siblings of children with diabetes or pervasive developmental disorders demonstrated greater social competence and prosocial behavior than siblings of children without disabilities. Further findings have indicated that older siblings show signs of growth, experience enhanced maturity, supportiveness, caring, compassion, responsibility, independence and increased family cohesion (Barbarin et al., 1995; Chesler et al., 1992; Sargent et al., 1995).

Researchers have noted, however, that although siblings' general psychological functioning may not be impaired, their social adaptation may be vulnerable (Drotar, Crawford & Bush, 1984) and that "minor dysfunction as an indicator of distress" may be evident (Carpenter & Sahler, 1991, p. 202). Lobato et al. (1988) also suggested that illness or disability is best described as a risk factor for sibling maladaptation which is mediated by constellation variables, family adaptation and functional patterns, and impairment characteristics.

Indeed, similar to literature on the impact of TBI on family stress and functioning, many interpretations exist for the various findings (positive, neutral or negative) among siblings. In several studies, characteristics of siblings have been directly or indirectly related to adjustment to their brother or sister's illness or disability. These characteristics include sociodemographic factors; previous functioning; coping resources; and perception of disability or illness (Houtzager et al., 1999; Lobato et al., 1988). In addition, family variables related to the adjustment of siblings include parental coping behavior, family functioning, parental distress, family

dynamics, as well as family life-events and pre-existing problems. The ill child's condition, such as the onset, etiology, course or phase, prognosis, visibility and functional impairment, may also impact on sibling adjustment (see Houtzager et al., 1999 and Lobato, et al., 1988 for full review of the impact of these variables). Some evidence suggests that sibling constellation characteristics may even be more influential on sibling outcomes than in children with typically developing siblings (Breslau, 1982) due perhaps to the greater stresses of their situation (Lobato, et al., 1988).

In contrast to these studies there is a body of literature that does not interpret the impact of disability or illness on siblings from either standpoint (Drotar & Crawford, 1985; Tritt & Esses, 1988). These researchers have shown that siblings are within the normal range of functioning and adjustment (Lobato, 1983; Lobato et al., 1988) and that even though chronic illness or disability “may present several upsetting and uncomfortable situations [for siblings], most ... cope with it, especially over time” (Kupst, 1986, p. 84). Indeed, Lobato et al., (1988) stated that

Group research generally does not support the popular belief that siblings of disabled and chronically ill children exhibit more problems in overall psychological adjustment than do siblings of able children. There is no uniform or direct relationship between a child's illness and psychopathology among his or her siblings (p. 222).

Despite this conclusion, research continues to report on the psychosocial, behavioral and emotional adjustment of siblings of children with special needs. Given the wide range of variability within these findings, however, very little is known about

the actual issues as perceived by the siblings or the processes siblings employ to manage the situations they find uncomfortable.

Summary

The studies conducted on siblings of children with an ABI have indicated that siblings' lives are affected for as long as five years post-injury (Orsillo, et al., 1993) and may possibly be "forever changed" (Gill & Wells, 2000). These studies also suggest that siblings assume greater responsibilities (Gill & Wells, 2000; Willer et al, 1990), experience emotional upheaval and stress, changes in their lifestyle, and overwhelming concern for their injured siblings' future (Willer et al., 1990). These issues typically go unaddressed (Kneipp, 1996), or are repressed by the siblings (Willer et al, 1990). Although a small amount is known about the possible consequences and outcomes for siblings, there is a clear need for an understanding of the holistic process of adaptation among siblings. A clear understanding of the underlying problems, their causes, consequences and the processes employed to manage these issues is essential to inform service provision. Given that a large responsibility for care and rehabilitation falls to the family, it is important to understand the impact of an ABI on siblings as they are likely to be an important component of an injured child's lifetime of support.

Although very little research exists on siblings of children with an ABI, clearly there exists a wide base of literature examining the impact of childhood illness and disability on siblings and their relationships. Many studies show that siblings and their relationships may be adversely impacted, while others suggest that the illness or disability may actually have a positive impact. In addition, it appears that there exists a

plethora of potentially confounding and mediating variables to account for when trying to understand this literature.

Using this past research to assess and understand how siblings cope and adjust to an event such as an ABI provides little insight into what siblings perceive to be their main issues of concern and how they go about coping. There are many different suggestions for how siblings are impacted psychologically and emotionally, but little information about how they cope and the processes they employ to cope. “We leave this review of the literature confused....We are still, many studies later, in the words of ... Strauss (1984, p. 10) ‘in the realm of terra incognita’” (Bluebond-Langner, 1996, p. 9).

Past research fails to provide a comprehensive framework for understanding the process regarding how and why a chronic illness or disability, such as an ABI, impacts on siblings. These shortfalls ultimately impact on the ability of health professionals to provide informed and appropriate interventions to support siblings and thus, the family unit. It has been suggested that the shortfalls of such research stem from the underlying, atheoretical approach inherent in many of the designs. Therefore, past research on siblings of children with an ABI, chronic illness and disability highlights some important issues, methodological difficulties and research considerations for conducting future research in this area.

CHAPTER 2

METHODOLOGICAL ISSUES FOR CONSIDERATION: PAST SIBLING RESEARCH AS A GUIDE TO DESIGNING THE CURRENT STUDY

As highlighted in the previous chapter, research examining the impact of an ABI, chronic illness, and disability on siblings has been equivocal and contradictory, focusing mostly on psychosocial outcomes rather than the processes of adjustment. The inconsistencies in the findings to date make it difficult to draw conclusions about how, or even if, siblings of children with conditions such as an ABI, are affected by the experience. Bluebond-Langner (1996) argued that this lack of understanding is caused by the quantitative philosophy that has underpinned most previous studies.

For example, past research has been dominated by a deductive approach that has examined a predetermined set of assumptions about the dysfunctional aspect of having a sibling with an ABI or an illness. Most research (both qualitative and quantitative) has been descriptive or has involved examination of simple bivariate causal relationships. Little consideration has been given to the complex relationships between variables over time. Much of this past research has been based on the assumption that clinically significant outcomes will be apparent and that existing clinical models can account for this experience. Sibling research that is dominated by a predetermined approach lacks sensitivity to identify subtle issues in coping (positive or negative) and is, therefore, limited in its ability to describe people or processes (Houtzager et al., 1999). The processes that assist resiliency, however, reveal more about how individuals cope, and what their intervention needs include. Clearly, future research needs an inductively derived theoretical framework to guide the selection of mediators and variables appropriate to examining sibling adjustment. In an absence of

such a framework, research merely risks adding to the piecemeal approach that has dominated this area to date (Houtzager et al., 1999; Perlesz, et al., 1999). A comprehensive framework explicating the process of sibling adjustment to an ABI is crucial to inform the development of useful interventions for siblings.

The aim of this research, therefore, is to inductively develop a comprehensive understanding of the issues that siblings of children with an ABI perceive to be their main concerns and how they go about resolving these concerns. A grounded theory method, which aims to discover an integrated and parsimonious theory through rigorous, systematic and simultaneous sampling, data collection and analysis, was considered an appropriate design for understanding more about siblings of children with an ABI. According to Yee (2001) “grounded theories are ideal in a study domain that is filled with disparate substantive theories, each claiming to have the ultimate answer to a problem” (p.6).

The shortfalls of previous studies, nonetheless, highlight important research considerations for this study and provide important justification for using the grounded theory method. In particular, the shortfalls regarding outcome assessment, over-reliance on parental reports, and heterogeneous samples are discussed. The grounded theory method proposed for addressing these shortfalls in the current study are then reviewed.

Outcome Assessment

Research conducted on siblings of children with an ABI, disability and illness has largely been approached from “a deficient or disease perspective” (Drotar & Crawford, 1985, p. 360). Studies are often designed around the predetermined

assumption that siblings of people with disabilities were inherently at risk for psychiatric and psychosocial difficulties (Bluebond-Langner, 1996; Cuskelly, 1999). This assumption has led to a reliance on a range of standardized instruments measuring outcomes, such as depression, anxiety, social and emotional dysfunction. Studying siblings from this framework, however, is inappropriate. Given the fact that siblings are not a clinical population, such measures are likely to suffer from a ceiling effect. Further, because they predetermine outcomes to be measured, many important processes may be overlooked. Such an approach lacks sensitivity to identifying alternative issues in the sibling population (Bluebond-Langner, 1996; Houtzager et al., 1999) and does not account for the potential of positive outcomes. This type of research also fails to explicate the processes of coping.

Carpenter and Sahler (1991) noted the inappropriateness of using predetermined measures to assess sibling adaptation. They argued that such measures are not sufficiently sensitive to detect subtle, yet important changes in sibling adjustment, nor are they specific enough to detect or define issues that contribute to sibling maladjustment if it is evident. This lack of sensitivity is highlighted by deductive, predetermined studies using the same measures, but reporting different outcomes. For example, several researchers (Breslau, 1982; Breslau et al., 1981; Breslau & Prabucki, 1987), using the Langner Psychiatric Inventory (Langner et al., 1976), found higher levels of psychiatric difficulties in siblings of children with special needs when compared to control groups, as did Lobato et al. (1987) using the Child Behavior Check List (CBCL) (Achenbach & Edelbrock, 1983). However, also using the CBCL, Ferrari (1984) and Bischoff and Tingstrom (1991) found no differences between siblings and comparison groups. Such inconsistent findings have typically

been found across studies using the same measures. These inconsistencies could be due to the inadequate reliability of some of the scales used (Langner et al., 1976; Perlesz et al., 1999), but are more likely to be due to their propensity to identify issues that have little clinical significance to the siblings being assessed (Cuskelly, 1999).

Similarly, Gan and Schuller (2002) agreed that regarding ABI “most family assessments are inadequately sensitive to particular issues specific to brain injury” (p. 312). In this regard discrepancies have emerged across different measures. For instance, Rivara et al. (1992) found deterioration in family functioning for up to 3 years post-injury in families of children with severe TBI using ratings by external observers. However, when assessed with standardized parent self-report measures, deterioration in family functioning was not evident. Rivara and her colleagues concluded that the impact of an ABI is more likely to be found in specific aspects of family functioning rather than on the global measures that are often used in family research. Similarly, Wade et al. (1995) suggested that the use of generic instruments can obscure the stresses and changes in family functioning that are unique to TBI. They noted that using interview or observational measures rather than caregiver reports is likely to identify issues that may otherwise remain hidden.

The unreliability of some quantitative measures is further highlighted by the fact that the incidence of depression in families of people with an ABI has been found to vary between 24 and 52% (Mintz, Van Horn, & Levine, 1995). Depending on the measure used, between 48% and 76% of the caregivers show no evidence of distress. Perlesz et al. (1999) noted that this variability may be due to the limited response categories offered to caregivers and siblings in quantitative measures. Such measures are biased in that they are almost always negative, not leaving the

caregivers/respondents the opportunity to report on positive changes or outcomes after TBI. On the other hand, however, utilizing scales that pre-determine the existence of particular coping resources (either positively or negatively) may in fact artificially promote their importance. “By simply measuring these variables, researchers may inadvertently assure their existence” (Catalano, 2001 p. 13).

Bluebond-Langner (1996, p. 9) argued that implicit in negative (or positive), predetermined approaches “is the notion of the disease or illness as an entity that has x, y, or z effects”, and that this method is inappropriate because any response to a traumatic situation will be a complex process. Although certain regularities in the process are possible to detect, post hoc, “the end states are not necessarily wholly contained in its beginnings” (Davis, 1963, p. 10, cited in Bluebond-Langner, 1996, p. 9). Instead, Bluebond-Langner stated that research should aim to discover the patterns of response to a chronic illness or disability, an approach that is consistent with family systems theory and runs counter to the notion of “cause and effect”. As eloquently described by Bluebond-Langner in relation to families of children with cystic fibrosis,

Understanding the impact of [a child’s illness or disability] on well siblings does not come from searching for something wrong in their lives nor does it come through the identification of some form of pathology or from the discovery of abnormal behavior caused by a trying situation. Rather, understanding lies in appreciating how the family, including well siblings, goes about preserving its integrity, living life as it is, in the face of [the illness’] intrusion (Bluebond-Langner, 1996, p. xiii).

In recognition of the shortcomings of predetermined global measures to assess family functioning specifically associated with TBI, recent researchers have

constructed new measures of family stress and adaptation that are equipped to identify the unique stresses and challenges of pediatric TBI on the family. For example, Taylor et al. (1995) developed the Family Burden of Injury Interview (FBII), based on data derived from focus groups with parents of children with TBI about their perceived experiences and needs. Although the FBII explores parent perceptions (self-report) about the reactions of sibling's to a child's TBI, no measures have been developed to assess the unique issues for siblings.

Thus, to avoid problems that are inherent in deductive approaches that seek outcomes based on predetermined hypotheses, without regard to process of adjustment and coping, Perlesz et al. (1999) have suggested that "more qualitative research and in-depth interviews with families would assist in enhancing understanding of the pattern of adaptation to TBI within families" (p. 25). Similarly, Kosciulek (1994) suggested that future research include qualitative methods to capture the multidimensional nature of family coping following ABI.

Over-Reliance on Parental Reports

In addition to the use of predetermined measures in previous studies, there has been an over-reliance on the use of maternal reports about sibling functioning rather than reports derived from siblings (Cuskelly, 1999; Wade et al., 1997). Although some argue that mothers are reliable informants, several researchers have found large discrepancies between sibling self-reports and parental reports on the same measures. For instance, Walker (1988) found a 44% disagreement rate between the reports of siblings and their parents about how they were coping with a sibling who had cancer. Menke (1987) also found that although parents and siblings of chronically ill children

agreed that their situation was worrisome, they did not agree about the nature of those concerns and worries.

Further, study methods that allow children to report without the assistance of their parents are equally important. Carpenter and Sahler (1991) developed the Sibling Perception Questionnaire for 6 to 17 year old siblings of children with cancer. However, parents were instructed to assist younger siblings to answer the questions when necessary. Given that siblings may not wish to share their private thoughts with parents (Bluebond-Langner, 1989), especially those thoughts relating to the impact of cancer on their family, this procedure may have had implications for the accuracy of the findings. Therefore, it is crucial that future research utilizes research methods that are age appropriate and allow siblings to express their point of view freely and without the input or influence of their parents.

Heterogeneous Groups

Based on the assumption that all disabilities impact on siblings in the same way, many studies in this area have not differentiated between diagnostic categories. Not surprisingly, approaching the study of siblings in this way adds to the inconsistency in the findings and confuses the rehabilitation needs of siblings.

A number of researchers have confirmed that different disabilities and illnesses are likely to have different effects on siblings (Noh, Dumas, Wolf & Fisman, 1989; Ryde-Brandt, 1992). For example, Fisman et al. (1996), in a three year longitudinal study found that siblings of children with Pervasive Developmental Disorder had significantly more internalizing difficulties than siblings of children with Down Syndrome. Similarly, McCubbin and Patterson (1983) found that ambiguity in a

child's diagnosis and prognosis was a significant factor contributing to stress in the family. These findings provide convincing evidence of the need for research to focus on single diagnostic categories in sibling research (Cuskelly, 1999). Such research can identify the unique support needs of particular groups.

Although the small number of studies conducted on siblings of children with TBI has addressed this limitation, it has neglected to explore the impact of non-traumatic ABI on siblings. Indeed, children with traumatic and non-traumatic ABI experience similar disability characteristics regarding onset, physical, psychosocial and behavioral outcomes, and are often referred to the same rehabilitation services (Appleton & Baldwin, 1998). Thus, it is essential that siblings of children with traumatic and non-traumatic ABI groups are included in future qualitative, exploratory research. Including siblings from both groups is particularly important for providing depth and breadth of information so that a thorough understanding of the conditions regarding the process of sibling adjustment to an ABI can be identified.

Summary

Clearly, there exists a need for inductively derived research to provide a theoretical framework, grounded in data, to inform the development of hypotheses and measures that are sensitive to the *actual* rather than theorized experiences and needs of siblings. Indeed, Shmerling, Schattner and Piterman (1993, p. 619) observed that “clinical problems are often complex, contextual and influenced by the interaction of physical, psychological and social factors” and unique to particular health issues. To increase the validity of questionnaires in mental health research, and ultimately understanding and effective practice, Powell, Single, and Lloyd (1996) stated that it is

crucial that the content of a topic area under investigation is explored in depth and derived from the people involved in the unique situation.

Qualitative Research: Addressing Previous Limitations

Qualitative methodologies have the ability to offer insight into “why” and “how” phenomena occur (Rich & Ginsburg, 1999). It is, therefore, essential when investigating a relatively new area, to first uncover the problems and generate hypotheses from the people concerned (Rich & Ginsburg, 1999), rather than aim to verify a set of predetermined assumptions. As little is known about the processes and experiences of siblings of children with an ABI, it is timely and vital that a qualitative approach is undertaken. According to Rich and Ginsburg (1999), “quantitative enquiry lacks the ability to look at the complex interplay among factors that produce individual choice and behavior” (p. 372). Although it cannot look for trends among large groups of siblings, qualitative research is an ideal approach to elucidate how a multitude of factors interact to form people's perspectives and guide their behavior. Given that little is known about the issues and problems as well as the processes by which siblings adjust to an ABI, coupled with the methodological shortcomings of predetermined approaches to research, a qualitative approach is an essential step toward a better understanding of siblings’ issues and needs.

Considerations in Qualitative Research

Limitations of past qualitative studies have contributed to the low level of their influence. For example, qualitative research often fails to capture the complexities and processes involved in the participants’ experiences. Most qualitative research

conducted on siblings has been descriptive (Gill & Wells, 2000), and has lacked discovery and conceptual depth (Becker, 1993). Typically, this research has simply reported major categories or themes relating to the participants' experience (Becker, 1993), but has failed to discover the underlying social or psychological processes at an abstract level. Therefore, the results of such studies include lists of categories and themes, but no conceptualization of the tentative relationships among the categories and themes constructed, nor an identification of a core category or process that accounts for a major portion of the variation among categories (Becker, 1993). Further, data collection and analysis is often conducted through a predetermined lens or interpreted through an existing theoretical framework. Thus, expression of the problem as perceived by the participants is often stilted and remains undiscovered. Further, qualitative research often neglects to make its methodologies and rigor explicit and accountable (Sandelowski, 1986), calling into question the applicability of their research findings.

According to Rich and Ginsburg (1999), the first level of scientific rigor is achieved by using research methods appropriate to the subject matter. Rigor is maximized in research that selects methods that are the most sensitive to the subject being studied (Kirk & Miller, 1986). In this regard, the application of the grounded theory method in this study will address many of the shortcomings of previous qualitative and quantitative research. Grounded theory includes strategies for research that provide a rigorous means of obtaining rich in-depth data. The grounded theory method (Glaser, 1978; 1992; 1998; Glaser & Strauss, 1967; Strauss & Corbin, 1998) therefore, was considered to be the most appropriate, rigorous and systematic inductive method to discover the impact of an ABI on siblings.

A Grounded Theory Approach to Understanding Siblings of Children with an ABI

“Grounded theory is the systematic generation of theory from data.” (Glaser, 1998, p.12) and is the most widely used qualitative methodology in the social sciences today (Punch, 1998).² Rennie, Phillips and Quartaro (1995) asserted that “psychology suffers from an elaborate research technology that overemphasizes theory verification and impairs thinking and discovery ... Grounded theory is an advanced approach to research that can address the crisis of method in psychology” (p. 141).

Unlike the deductive approach of previous studies that aims to verify hypotheses or explore a given research problem using predetermined outcome measures, grounded theory aims to discover the problem as perceived by the participants, as well as discover how the participants resolve this problem (Glaser, 1992; 1998). This aim is achieved through a complex methodological process requiring a completely different philosophical lens to that required for understanding verification studies. Unlike verification studies that are linear and involve pre-selected research problems, samples, measures and theoretical frameworks to guide interpretation, grounded theory is inductive and its methods cyclical (Glaser, 1978). Research problems are not fully determined prior to data collection, sample size and constitution are unknown, and no existing theoretical structure is applied to the data for interpretation (Glaser, 1998).

Instead, these factors emerge through the constant comparison of the emerging data, simultaneous sampling, data collection, and data analysis (see Figure 3.1), which

² Grounded theory is a general method that applies well to qualitative data however, it is not only a qualitative methodology. Grounded theory is also applied in quantitative methods (Glaser, 1998).

continues until general categories and concepts (themes), relationships, and the conditions under which they vary are discovered and become a parsimonious theory (Yee, 2001). The theory goes beyond description to conceptualization, describing the tentative relationships among emergent categories and how they relate to a core category (or core variable) that accounts for the major portion of variation in the theory.

Thus, the ultimate aim of a grounded theory study is to develop a theory that is relevant and includes processes, strategies, and conditions that predict, explain and describe behavior (Glaser & Strauss, 1967). A grounded theory should also “stand on its own [and provide] a means whereby existing theory can be further expanded” (Yee, 2001, p.5).

Interpretations of emerging hypotheses are constantly verified and checked by the constant comparative method (Glaser, 1998 – see Chapter 4). As a result, grounded theory addresses another limitation often evident in both quantitative and qualitative studies, namely the fact that interpretations of data patterns are “usually conjectured out of impressions, personal projections and coincidental literature” (Glaser, 1998, p. 12). Interpretations of emerging hypotheses in grounded theory, however, are constantly checked against emerging data to insure that they are grounded in the data, and are not just appealing guesses (Glaser, 1998).

Thus, regarding the limitation of past studies focused on verifying predetermined hypotheses about “cause and effect”, rather than understanding processes of coping, grounded theory enabled the discovery of a rigorously and systematically derived theory explicating how siblings perceived life following their brother or sister’s ABI, and the processes they employed to manage the situation.

Size Does Not Matter

Given that large sample sizes are difficult to attract in the area of siblings of children with an ABI (McMahon, et al., 2001; Orsillo, et al., 1993) grounded theory was considered an appropriate design. Small sample size is of little relevance in a grounded theory study (Glaser, 1998), because the purpose of grounded theory is to discover a new theory directly tied to the reality of the participants, not to verify an existing theory beyond that discovered by the saturation of categories (Rennie et al., 1995). Indeed, many grounded theory researchers (e.g., Rennie, et al., 1995; Rose & Jevne, 1995) have described comprehensive theories developed from five or ten interviews.

Sample sizes in grounded theory, and other qualitative research, are typically small because of the large volume of verbal data that is obtained from multiple contacts with participants (Sandelowski, 1986). In addition, sampling in grounded theory is theoretical, not statistical, leading to a smaller and more specific sample. Participants are selected initially because they are perceived to be able to illuminate the phenomenon being studied, and subsequent sampling is based on the findings that emerge from the analysis (Glaser & Strauss, 1967; Sandelowski, 1986). Thus, sampling (size and type of participant or source) is not determined prior to data collection, but evolves with the analysis and findings. Representativeness is irrelevant and the purpose is to present an integrated set of hypotheses that can later be tested through verification studies if necessary.

Qualitative studies are designed to investigate a particular area of interest in depth in order to reach a better understanding of the universal (Lincoln & Guba, 1985). This characteristic makes it possible to work with small sample sizes, focusing on

depth of experience, rather than generalizability (Lincoln & Guba, 1985). The focus of qualitative research is on detailed information and “thick descriptions” (Geertz, 1973) and seeking patterns in complexity rather than simplifying it into a consensual overview.

The grounded theory method also embraces the use of variability within a particular population because this variability allows the boundaries and conditions of a theory to be defined and tested. The more variability that can be accounted for in a grounded theory, the greater the explanatory power of the theory. Thus, grounded theory was an appropriate methodological design that transcended potential research limitations associated with small samples.

From the Mouth of Babes

Grounded theory is based on the assumption that reality is socially constructed, complex, and constantly changing, and that behavior can be investigated through the human perceptions, understandings, and beliefs that motivate them (Glaser, 1978). Thus, in order to provide an opportunity to discover theory, data collection methods must be undertaken in an appropriate manner to assure credibility of data (Strauss & Corbin, 1998). The principles of grounded theory are consistent with the aims of phenomenology, which focuses on the depth of human experience to understand a situation from the participant’s frame of reference (Baker, Wuest & Stern, 1992). Thus, utilizing this design will eliminate problems in previous research, such as the reliance on parental reports. The design will also overcome the limitations of superficial self-report questionnaires.

The Current Study

In summary, this study aimed to understand how childhood ABI impacts on siblings. This study was considered timely since previous research has tended to focus on verifying predetermined hypotheses and adjustment outcomes, rather than understanding the process of adjustment as perceived by the siblings. Although previous studies have highlighted some important issues likely to face siblings of children with an ABI, there exists a dearth of literature about how siblings perceive and manage these issues. This study employed the grounded theory method to address this gap.

Consistent with the grounded theory method, no problem statement was outlined at the start of this study. The goal was to discover, through inductive simultaneous data collection and analysis what siblings of children with an ABI perceived to be their main issues of concern and how they managed and coped with these issues and concerns. Thus, the current study proposed to discover a theoretical model explicating how an ABI impacts on siblings. The development of such a model is essential to inform and guide future research so that it does not continue to obscure the real issues facing these children. It is also essential that this theory be grounded in data generated by the siblings themselves rather than from practitioners or parents. Since child and adolescent siblings are dependent, integral members of the family system, a conceptual understanding of the process of their adjustment to a brother or sister's ABI should be explored.

This research will also provide an appropriate means of developing and enhancing the utility of constructs and hypotheses used to examine the adjustment of siblings of children with an ABI in future. Indeed, Glaser (1978) suggested that

quantitative methods assist in verifying grounded theory, but that grounded theory provides a framework from which grounded hypotheses are derived. The grounded theory design was also appropriate because it enabled the use of methods that accommodated methodological limitations inherent in this population, namely its heterogeneous nature and the inability to attract large samples.

Finally, according to Rich and Ginsburg (1999), "initial steps in developing intervention strategies must employ qualitative research methods to gain a contextual understanding of youth, their behaviors, and the nature of their lives and worlds" (p. 377). Thus, the current study will not only address the methodological shortcomings of past research by developing an appropriate theory of the coping and adjustment processes employed by siblings, but will also inform future research and the development of interventions specific to this population. The following chapters describe how data derived from interviews with siblings and other data sources were transformed into a comprehensive theory explicating the sibling experience following an ABI.

CHAPTER 3

METHOD

This study employed a grounded theory design to systematically generate a parsimonious theory to explain the main issues of concern for siblings of children with an ABI and how they resolved these concerns. A total of 53 personal interviews were conducted recursively with twenty child and adolescent siblings of individuals with an ABI, four adult siblings of individuals with an ABI and four child and adolescent siblings of individuals with congenital disability. In addition, observational and secondary data were collected from various sources (e.g. hospital staff and parents). From these various sources, an emerging theory was developed, explored, elaborated and verified without predetermined hypotheses or prior selection of questionnaire categories.

Consistent with grounded theory methodology, the processes of sampling, data collection, and analysis were dynamic and cyclical, and continued until the data became saturated (see Figure 3.1). Saturation occurred when new data ceased to reveal new information. Although sampling, data collection and analysis were inter-related, an artificial distinction has been made between them for the purpose of clarity. The methods of sample selection, namely theoretical sampling, and data collection will be described in this chapter and the processes of data analysis will be presented in Chapter 4.

Figure 3.1. A model depicting the principles of theoretical sampling utilized in this study.

Theoretical Sampling

In contrast to traditional sampling methods applied to deductive research, this study employed the principles of theoretical sampling (Glaser, 1978; Strauss & Corbin, 1998). Sample size and constitution were not predetermined, but were selected on their potential to produce theoretically relevant data and to extend the emerging theory towards theoretical completeness (Glaser & Strauss, 1967). As concepts and categories emerged from initial data analysis, that was derived from a purposive sample, additional data sources were systematically selected (or theoretically sampled) according to their perceived potential to discover, expand, verify, refine and interrelate the conditions, properties and boundaries of the emerging theory, its categories and hypotheses (Glaser, 1992). Theoretical sampling was guided by the emergence of the categories and their related concepts.

Consistent with the grounded theory method, this form of data collection continued until the categories reached theoretical saturation and new data no longer enhanced the theory (see below for more detail). Theoretical sampling was the process of sampling appropriate sources in order to confirm the emerging theory against incoming data (Glaser, 1978). Thus, “validation is built into each step of analysis and sampling” (Strauss & Corbin, 1998, p. 211).

Representativeness in grounded theory concerns the data, not the sampling units (Strauss & Corbin, 1998). The theory is not about people, but about the processes people use (Yee, 2001). Therefore, as opposed to traditional research, “all is data” in a grounded theory study (Glaser, 1998). Thus, a range of data sources can be sampled in order to expand and develop the theory. For instance, in this study, data was sampled from primary sources (raw data collected by the researcher) and secondary sources

(data gathered through other sources) at different stages of the analysis. These data sources are presented below.

Primary data sources

- Interviews with child and adolescent siblings of individuals with an ABI (Purposive sample),
- Interviews with adult siblings of individuals with an ABI
- Interviews with child and adolescent siblings of individuals with congenital disability,
- Observational data (i.e. collected in interviews with siblings),
- Sampling previously collected data (i.e. re-coding for missed concepts and categories in initial analysis),
- Sampling and interviewing previously interviewed participants.

Secondary data sources

- Anecdotal accounts from interviews with hospital staff regarding the sibling experience,
- Informal discussion with parents regarding the sibling experience,
- Literature (e.g. autobiographies of other siblings, case studies, quantitative and qualitative research, formal theoretical literature).

In summary, theoretical sampling was the process whereby the selection of participants and interview topics (see interview protocol below) were influenced by the emerging analysis and evolved during the course of the study (Glaser & Strauss, 1967).

As indicated above, however, the initial sample was purposively chosen, as directed by the main research focus.

Initial Sample Selection: Maximum Variation Sampling

Purposive sampling involves the selection of “information-rich cases”, which offered in-depth accounts of the central research issues (Patton, 1990 p. 169). This sampling strategy was appropriate for the grounded theory method because participants were selected based on their likelihood to represent the phenomenon being studied (Willoughby & Keating, 1995). Indeed, Miles and Huberman (1984) recommended that initial samples should be selected from relevant sources that have the potential for rich information.

Further, Strauss and Corbin (1998) recommended that initial sample selection should ensure as much variability as possible to avoid foreclosing prematurely on the discovery of concepts and categories. This view is in line with Lincoln and Guba (1985) who stated, “for the naturalistic approach, maximum variation sampling is most useful” (p. 233). Variability is also a good method for controlling sample bias (Miles & Huberman, 1984) and ensuring saturation of categories (Glaser, 1978). Given the above considerations a maximum variation sampling plan (Patton, 1987; Punch, 1998) was implemented to deliberately seek as much variation and range of information as possible from the initial sample.

As previously described, obtaining a sample of siblings from a clinical area such as ABI is difficult, especially when accounting for potential heterogeneity in the population (e.g. time since injury, type of injury, injury severity). The maximum variation sampling method, therefore, aimed to capture and describe the central themes

that cut across participant variation. The maximum variation sampling strategy turned the apparent weakness of small and variable sample size into a strength by applying the logic that, “any common patterns that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared aspects [of participants]” (Patton, 1987, p. 53). Thus, this sampling method was highly compatible with the aims of the research since “the more diverse the data, the more complete the theory is likely to be” (Yee, 2001, p. 9).

Accordingly, minimal restrictions (i.e. inclusion and exclusion criteria) were placed on the selection of the initial sample of siblings, particularly in relation to such attributes as sex, birth order, time since injury, age at time of injury, cause of injury, type of injury, injury severity, and living arrangements. In fact, according to Glaser (1998), demographic variables have to earn their way into the theory and are irrelevant until proven otherwise.

However, as the study focused on the experience of child and adolescent siblings of ABI survivors, the major selection criteria was age. Siblings between ten and eighteen years of age who were either children or adolescents when their brother or sister sustained an ABI were invited to be involved in the study. Siblings younger than ten years of age were not selected due to the difficulty in eliciting useful interview data from this age group (Geldard & Geldard, 1998).

Given that no two individuals respond identically to circumstances (Royal et al., 1995), and given that grounded theory aims to seek representitiveness of data rather than populations (Strauss & Corbin, 1990), it was considered methodologically reasonable to interview siblings from the same family and consider them to be independent participants. Due to the qualitative design of the current study, issues

associated with sampling siblings from the same family in quantitative research, such as, data replication or the confounding of variables (Cuskelly, 1999) were not relevant. Further, interviewing two siblings from the same family has been documented as a useful technique in other grounded theory or qualitative research exploring siblings of children with Attention Deficit and Hyperactivity Disorder (Kendall, 1999) and children with cancer (Royal, Headings, Molnar & Ampy, 1995).

Sampling Procedure

Siblings were recruited from the main children's trauma hospital and the two statewide community agencies assisting people with an ABI in Queensland. The sites selected for recruitment of the siblings, included the Rehabilitation of Children with Acquired Brain Injury and Neuromuscular Disorders (ROBIN) unit at the Mater Children's Hospital, the Acquired Brain Injury Outreach Service (ABIOS) and the Brain Injury Association of Queensland (BIAQ). Selection of siblings from a variety of sources further increased variability in the sample by ensuring greater range in time since injury. For example, the hospital presented an opportunity to select siblings whose brother or sister was in the initial phase of their recovery and rehabilitation process, whereas the community agencies allowed sampling to focus on siblings whose brother or sisters were in either transitional rehabilitation or long-term phases of recovery.

Siblings whose brothers or sisters were outpatients, recipients of the outreach service or members of BIAQ were invited to be involved in the study. With the assistance of the ROBIN team and the ABIOS team, siblings were selected based on their age and the likelihood that participation in the study would not be harmful. An

invitation to participate was sent to those participants. Staff then contacted potential participants who did not reply to the letter by telephone or in person during out-patient appointments. This procedure was important for increasing the variability and representativeness of the sample and minimizing the sample bias associated with including only those participants who responded enthusiastically (Miles & Huberman, 1994).

Letters were posted to all BIAQ members (usually family-based membership) inviting siblings who were between 10 and 18 years of age to participate in the research. Only two adolescent siblings responded to this request, perhaps reflecting the bias toward adult membership of BIAQ. Nonetheless, a total of 20 siblings between 10 and 18 years responded to the research and were subsequently interviewed.

Eighteen of the twenty participants were sampled for further interviews, some on three occasions. This form of theoretical sampling was applied in the later stages of analysis (see Theoretical coding, Chapter 4) as is common in grounded theory (Strauss & Corbin, 1998).

Sample Selection Based on Theoretical Sampling

To verify the emerging framework, additional sources were sampled. Glaser (1978) warned, however, that to avoid the study becoming derailed from its relevance, fit and functionality, sampling outside of the main area of research (i.e., child and adolescent siblings of individuals with an ABI) should occur only when concepts, categories and processes have been identified from the initial sample of focus.

Adult Siblings

Four adult siblings who were children or adolescents when their brother or sister sustained an ABI were theoretically selected to further explore the boundaries and conditions of the emerging categories. For example, data from adult siblings provided information about whether or not the emerging strategies and processes siblings used to manage an ABI were specific to childhood (i.e., the boundaries of the theory), and the factors that increased or decreased the implementation of such strategies (i.e., the conditions of the theory).

Topics explored through the inclusion of adult siblings included questions such as (1) *Are the concepts, categories and processes identified unique to siblings while they are children and adolescents or do these processes persist over time?* (2) *Do siblings view the situation differently in retrospect to siblings still experiencing it?* (3) *How do adult siblings cope with and view the situation?* This form of extreme case sampling aimed to verify conclusions and hypotheses as well as expand the emerging theory (Miles & Huberman, 1984). Extreme case sampling presents opportunities for learning the evolution of future recommendations (Patton, 1987). In selecting extreme cases, Miles and Huberman (1984) stressed the importance of talking to participants who are not actively involved or central to the phenomenon under study, but who are “neighbors” to it. Consequently, adult siblings were an appropriate sample source as they no longer lived with their brothers or sisters with an ABI, but had experienced the same circumstances.

Two of the adult siblings were recruited through the Department of Families, Youth and Community Care (DFYCC), one through the BIAQ and one was referred through a participant who was already involved in the study. This form of sampling

(whereby siblings already recruited for the study referred other siblings for participation) was necessary because the identification of adult siblings was difficult and response was poor. According to Patton (1990), however, this method is useful for accumulating information-rich cases. Recruitment of the adult sample ceased after four interviews because informational redundancy was reached in that the final interview added little new information to the emerging theoretical framework. Three of these participants were interviewed on subsequent occasions.

Siblings of Children with Intellectual Congenital Disability

Data from four interviews with siblings of children with congenital intellectual disability were sampled to further verify and elaborate the emerging categories and explore the applicability of the theory beyond an ABI.³ Obtaining interview data from siblings of children with congenital intellectual disability was another form of extreme case sampling. This data provided information that assisted to elaborate on the properties and conditions of the categories, and to define the boundaries of the theory. For example, in the original data, the experience of one sibling who was only an infant when her brother sustained an ABI seemed to differ from others, prompting such questions as, *“To what degree is the impact of ABI different for siblings who have not established a relationship prior to the ABI?”* An alternative question involved whether or not this finding was related to the cognitive ability of young children who were not

³Interviews with these siblings were conducted to pilot the interview protocol (see below). The pilot interviews yielded much in-depth data that made it possible to sample these interviews for information to extend the emerging theory. Thus, the pilot data was sampled in later stages of the analysis due to its perceived ability to extend the theory.

included in this study. Given the difficulties associated with interviewing children under 10 years, the decision to sample data from siblings of children with congenital intellectual disability seemed to be an appropriate way of exploring the gaps in the theory and accounting for variability in the data.

Further, transferability of findings to other settings in qualitative research is useful for expanding knowledge about the applicability of the theory (Lincoln & Guba, 1985; Polit & Hungler, 1999). Therefore, siblings of children with congenital intellectual disability were also considered an appropriate comparison group to explore the applicability and transferability of the resulting theory beyond an ABI. Indeed, a well-constructed grounded theory with a high level of abstraction should be able to account for and explain phenomenon that occurs outside the substantive area (Glaser, 1998).

The siblings of children with congenital intellectual disability were recruited through the Principals of three local Education Queensland Special Schools, who assisted in identifying children with intellectual congenital disabilities who had siblings between ten and eighteen years of age. Information packages were given to the school Principals who sent the packages home with appropriately identified students. Siblings who were interested in being involved with the research contacted the researcher directly. These siblings were interviewed and their data was analyzed and incorporated into the understanding of the emerging theoretical framework in later stages of the analysis (see Selective coding, Chapter 4).

Hospital Staff

The emerging theoretical categories also indicated a need to further explore the siblings' experiences in the initial phase of a child's hospitalization process, as this period was particularly stressful for siblings (see Chapter 5). However, exploring siblings' experiences first-hand during hospitalization in the acute phase of their brother's or sister's recovery process was not considered ethical. ABI is a very private experience for the family and is often fraught with anxiety and turmoil. Therefore, siblings were interviewed retrospectively about this phase of the recovery process and only siblings whose brother or sister was five months post hospitalization or more were interviewed.

Thus, rather than interviewing siblings whose brother or sister was still in hospital, one physician who had significant contact with families in the Intensive Care Unit (ICU) was interviewed regarding his perceptions and observations of the siblings' experiences during hospitalization. He was asked to provide his perceptions about siblings' behaviors, thoughts and feelings at this time. Observations were also made of the acute care setting.

Parents

In six cases, parents of the siblings interviewed volunteered information useful to understanding the sibling experience. As the analysis proceeded, and categories started to emerge, the data provided by the parents was theoretically sampled for its potential to expand the theory. Observer accounts of the siblings' behaviors were important because the strategies siblings employed to manage an ABI involved psychosocial and interactional elements that were intended to make a deliberate

impression on observers (e.g. parents, etc.). Gaining outsider accounts had the potential to verify the emerging theory (see Chapter 6). Observations and the anecdotal data were recorded and compared to the emerging analysis (see Selective coding, Chapter 4).

Literature as a Data Source

Once a grounded theory and core category had emerged from the data, literature in the field was reviewed and integrated into the theory. It is important to note that literature was not utilized as explanation, justification or proof of the emerging theory, but was analyzed, compared and contrasted to aid in the refinement of the theory (Glaser, 1998). In accordance with recommendations by Glaser (1978), however, sampling from the literature only proceeded once categories were well developed from the interview data and a core category had emerged, so that bias or pre-empting of categories was minimized. Literature, like the other data had to earn its way into the theory through the process of constant comparison (see Selective coding, Chapter 4).

Sample Size as Determined by Theoretical Saturation

As mentioned above, sampling and coding continued until the data appeared to be saturated. Evidence of saturation was observed when new data fitted into established concepts and categories, variation in the categories was described, interactional patterns were discernible, and the siblings' behavior in the context of the study could be predicted (Hutchinson, 1986). Although grounded theorists have suggested that sampling should continue until each concept is theoretically saturated

and no new codes emerge from the data (Glaser, 1978; Glaser & Strauss, 1967), the constraints of ethical procedures, time, resources and access to siblings of children with ABI influenced sample size in this study, to some degree. Indeed, Miles and Huberman (1994) questioned the feasibility of saturation in certain situations.

The longer we are in an environment, the more layers appear to surface, and the choice of when to close down, when to go with a definitive coding scheme or definitive analysis, can be painful. That choice may be dictated as often by time and budget constraints as on scientific grounds. When those constraints are relaxed, saturation can become a vanishing horizon – just another field trip away, then another.... (Miles & Huberman, 1994, p.62)

Indeed, Strauss and Corbin (1998) recommended that saturation be considered as a matter of the *degree* to which incoming data fails to add to the emerging theoretical concepts. Given the in-depth nature of the interviews in this study, however, sufficient regularity was found to support the emergent theoretical framework and indeed, data collected in the final stages of coding and analysis added little more to the understanding of the emerging theory.

Sample Characteristics: Primary Data Sources

The initial sample consisted of 13 male and 7 female ($n = 20$) siblings between the ages of 10 and 18 years (mean = 13.15, SD = 2.52), who were between 3 months and 16 years of age (mean = 10.05, SD = 4.15) when their brother or sister sustained an ABI. Time post injury ranged from 5 months to 10 years (mean = 3.2 years, SD = 2.78). The age of the injured siblings ranged from 4 years to 24 years at time of injury

(mean = 11.25, SD = 5.00). Eighteen of the siblings were school students and two were in full-time employment.

The four adult siblings were between 20 and 35 years of age (mean = 25.25, SD = 7.12) at the time of the interview and between 2 and 17 years of age (mean = 11.15, SD = 6.72) when their brother or sister sustained an ABI. Time post-injury in this group ranged from 3 years to 19 years (mean = 14.25, SD = 7.54). The age of the injured siblings ranged from 2 years to 16 years at the time of injury (mean = 8.75, SD = 6.80). Three of the siblings were university students and one was in full-time employment. Interestingly, and consistent with past research on siblings of children with congenital disability and illness, three of the four adult siblings were studying or working in the health care profession.

Consistent with statistics regarding the ABI population (Snow & Hooper, 1994), the child and adult siblings' family member with an ABI were predominantly male. A ratio of 14 boys to 5 girls had sustained an ABI across the child and adolescent sample. Five of the children with an ABI were pedestrians hit by a car, five acquired their injury through falls, four experienced a stroke or illness, four had been injured in motor vehicle accidents, and one was injured through physical abuse as a toddler. All children had sustained moderate to severe ABI as indicated by medical reports (Glasgow Coma Scale, Post-traumatic amnesia duration) and feedback from hospital staff regarding their perception of the severity based on physical and cognitive functioning. Half of the participants were older than their sibling with an ABI and half were younger. The age gap between participants and their siblings with an ABI ranged from 1 to 9 years (mean = 3.4, SD 2.03). Twenty-one of the child and adult siblings (from nineteen families) interviewed were from families with both biological parents

living in the home and three (from two families) were from single parent homes living with their mother. The participants all lived with their brother or sister at the time of the ABI. At the time of interview, the adult siblings and two adolescent siblings no longer lived with their brother or sister with an ABI. Although one adolescent sibling still lived at home, his older sister with an ABI had moved out.

The four siblings of children with congenital intellectual disability ranged from 11 to 18 years of age (mean = 14.75, SD = 2.87). One sibling was 4 years older than her brother with Down Syndrome; one was 1 year younger than her brother diagnosed with Down Syndrome, Aspergers and Attention Deficit and Hyperactivity Disorder (ADHD). Two siblings were sisters, one was 2 years older and the other was 5 years younger than their sister with Rhetts Syndrome. Two of the siblings lived in two-parent homes and the sibling pair lived with their mother. All siblings in this group lived with their sibling with congenital disability.

Detailed characteristics regarding the secondary data sources were not considered necessary as they pertained to the primary data sources. Any literature sampled is referenced in Chapters 5, and 6.

Materials

Initial interview data that was obtained from the 24 child, adolescent, and adult siblings of individuals with an ABI, and the four siblings of individuals with congenital disability, accounted for a major portion of the data collected in this study. Although this data was collected and analyzed at different time intervals in the analysis, all siblings were presented with the interview protocol presented below. Subsequent

interview protocols and procedures that were influenced by the analysis are also presented.

Interview Protocol

According to Patton (1990), interviewing as a research method assumes that “the perspective of others is meaningful, knowable, and able to be made explicit” (p. 278). Indeed, interviews enabled access to information about behaviors, situations and events in the world of the siblings. Interviews also allowed access to the perspectives, underlying belief systems, feelings, thoughts, motivations and meanings attached to the events that could not be directly observed or identified in a questionnaire (Patton, 1990; Rich & Ginsburg, 1999).

A structured interview that controls the interaction in a predetermined sequence and implicitly assumes that all respondents understand and interpret questions in the same way (Mishler, 1986) was clearly adversarial to the principles of grounded theory. Although unstructured interviews are more often used in grounded theory, they were not considered optimal for eliciting information from a child and adolescent sample. Children and adolescents can be shy, naturally laconic and have difficulty articulating information about their thoughts and feelings, especially in the face of a potentially threatening situation, such as an interview with a stranger about a sensitive topic (Geldard & Geldard, 1998). Fortunately, time and resources permitted the conduct of face-to-face semi-structured interviews, which were considered the most appropriate medium for interviewing young participants about a sensitive topic (de Vaus, 1991).

Further, this study was required to meet the stringent criteria for interviewing children proposed by the relevant Ethics Committee (National Health and Medical Research Council, 1999). Thus, questions and areas of exploration had to be identified

prior to interviewing the siblings and remain *reasonably* constant for the duration of the study. Although this requirement contradicted the recommendations of Strauss and Corbin (1998) and Glaser (1998) that the initial interview protocol change as it is driven by the analysis, most principles of grounded theory were retained.

The semi-structured interview consisted of broad issues with a flexible question format. Flexibility was important because it enabled topics to be introduced and explored at any point in the interviews as required by grounded theory. King (1994) warned against framing research questions in a way that reflects presuppositions or biases of the researcher, rather than allowing relevant data to emerge (Glaser, 1992).

The flexible Interview Guide

The interview protocol was developed utilizing King's (1994) criteria for creating interview guides. This criteria necessitated 1) personal knowledge and experience of the area, 2) a basic understanding of the research literature and 3) informal discussions with other professionals experienced in the research area.

As a Psychologist, the researcher had several years working with children and adolescents with an ABI and their families and was, therefore, cognizant of the area under investigation. Following the completion of many intake and counseling interviews with young adults with an ABI and their families, as well as home visits in a case management role, the researcher identified a gap in the understanding of issues pertaining to siblings of children with an ABI and the consequent lack of services for siblings. Thus, the researcher's knowledge and experience provided a good foundation for the enquiry into the experience of siblings.

Glaser and Strauss (1967) have cautioned against becoming too engaged with literature and theory in the relevant field before commencing data collection and analysis, as it may yield pre-conceived categories. They suggested that comparisons with the literature could be established after the emergence of categories through analysis. Conversely, Blumer (1978) believed that it was impossible to ‘ignore’ existing research and theoretical positions prior to the emergence of categories. Indeed, other theorists have suggested that a reasonable overview and understanding of the literature prevents the likelihood of irrelevant duplication (Punch, 1998). In an attempt to balance these extreme views, Grbich (1999) emphasized the importance of approaching the literature review lightly to enable an understanding of previous findings without dominating the design of the study or pre-empting the findings. Although only minimal literature exists in this area, a brief review was conducted to clarify existing knowledge and gaps prior to the development of the semi-structured interview. Following Glaser’s (1998) advice, the researcher also documented apparent biases and preconceptions relating to previous work experience in the field. This awareness made any biases explicit and avoidable during analysis.

To address King’s third criterion of avoiding bias in the questions, the interview guide was ‘audited’ (Lincoln & Guba, 1985) by two psychologists, one experienced in working with children and another in working with adults who have sustained an ABI and their families. This audit ensured that no pre-existing hypothesis, themes, or questions contaminated or directed the interviews, or had potential to bias the participants’ responses. The auditors held a Masters of child psychology and a Doctorate in Rehabilitation Psychology and both had extensive research experience in qualitative interviewing and analysis. These professionals also

read the protocol for its age appropriateness and assessed sensitive questions that may have been detrimental to the siblings. One of these professionals, who also assisted with inter-rater coding (described in Chapter 4), monitored any revisions to the protocol throughout the data collection process to ensure that no pre-existing or emerging hypotheses from the analysis were directing or leading the participant responses.

To pilot the interview guide, four siblings of children with congenital disability (described above) were interviewed. The siblings were presented with the same interview questions and procedure described below, however, the term ‘sibling with an ABI’ was replaced with ‘sibling with special needs’. In addition to completing the entire interview protocol, these participants were asked to identify any ambiguous questions and highlight any words or concepts that they did not understand. Only minor changes were made to the protocol as a result of the professional and pilot audits.

The final interview guide consisted of a standardized, but flexible joining and rapport building process (See Appendix A, Stage 1 and Stage 2) and five main *topics* identified (by the researcher and auditors) as useful for exploring the aims of the research (King, 1994). These topics included the siblings’ perspective in relation to 1) their family; 2) important life events; 3) the impact of their brother or sisters ABI on various areas of their life; 4) how much information they had regarding the events; and 5) how they coped with the ABI (see Appendix A, Stage 3). The language in the interviews was adjusted to suit the age and developmental level of the siblings.

The interview guide utilized a funnel sequence to explore the main topics. Specifically, the initial questions were broad (e.g., “How do you think ABI has

impacted on different areas of your life?”). In the case of minimal responses, prompt questions were used (e.g., “Tell me about any changes you may have experienced as a result of having a sibling with an ABI”; or “Tell me about any benefits or difficulties you have experienced as a result of having a sibling with an ABI”). More specific probe questions were used to further explore the siblings’ experience in-depth (e.g., “Tell me about an incident when X happened”; or “What was that like for you?”).

The initial questions concerned non-threatening issues that the siblings could easily answer without embarrassment or distress (King, 1994). Activities were incorporated into the questions to lessen the formality of the interview. Different communication methods, such as drawing, assisted in eliciting useful information that may not have been gained through conversation alone (Geldard & Geldard, 1998).

Siblings were also asked to draw a genogram of their family and friends and to plot, on a time-line, the most significant events in their life. For instance, siblings were asked to depict their answers to some questions in simple drawings using a wide range of colors. They were invited to be as creative as they liked, which further eased the interview atmosphere and built rapport.

Siblings were then presented with a large sheet of paper on which major categories (i.e. school, family, relationship with sibling(s), thoughts and feelings) were written in different colors. These categories assisted as a prompt for exploring the different areas of the children’s lives (especially for the younger children) and organized the interview process. These categories also maximized the elicitation of information when participants were laconic (King, 1994), yet avoided pre-determined and leading questions. This sheet also assisted siblings, especially the younger participants, to organize their thoughts and think about their lives in a variety of ways.

Finally, a sheet depicting different facial expressions of feelings was used to assist siblings to identify their feelings (See Appendix B).

The more sensitive questions regarding the impact of the ABI on the siblings lives (e.g. “How do you think ABI has impacted on different areas of your life?”) were addressed in the middle of the interview once rapport was formed. To avoid ending the interview on sensitive issues (King, 1994), the concluding questions aimed to focus the conversation on the future (“What advice would you have for other siblings going through the same experience in future?”) and on positive topics (“Tell me about some of the best times you have had with your sibling”).

To conclude the interview, siblings were asked if they wished to make any further comments regarding the topic, giving them an opportunity to gain a sense of completion and to address any issues of importance that had not been covered. Siblings were also debriefed about the process to ensure that any sensitive issues discussed were resolved and that the interview did not leave them distressed. Appendix A contains the interview guide including examples of typical prompts used to elicit information. An observation sheet was completed by the researcher following every interview (see Appendix C).

Interview Processes Following Analysis

In contrast to the flexible interview guide that aimed to generate in-depth thick description, the second interview following data analysis was more structured and purposeful. The aim of the second wave of interviews was to discover interconnections among emerging categories and concepts and to expand and verify the theory (see Theoretical coding, Chapter, 4). Thus, most child and adult siblings of

children with an ABI were re-interviewed and presented with more specific questions relating to the emerging model. Specifically, siblings were presented with examples of ‘mini-theories’ that emerged from the analysis as well as additional questions regarding the categories. Examples of the questions presented to siblings in the second interviews are presented in Appendix D.

The interview protocol presented to the ICU physician was developed and guided by the emerging gaps in the data (see Appendix E for interview questions) and aimed to expand and elaborate the core theme (see selective coding, Chapter 4). Information from parents regarding their perceived experience of siblings of children with an ABI was usually provided spontaneously in an informal conversation or by telephone call following the sibling interview.

Procedure

Ethical procedures prevented the researcher from contacting potential participants directly and necessitated the use of recruitment letters mailed by ROBIN, ABIOS, BIAQ, DFYCC and Education Queensland. The recruitment letters invited siblings to be involved in the study and included parent, child, and adult sibling consent forms (see Appendix F, G, H), which were returned to the researcher upon agreement to be involved. The older participants were recruited through word of mouth and networking and were contacted directly by telephone once verbal permission to do so was gained from the siblings’ who referred them.

Twenty-six siblings (siblings of children with an ABI and siblings of children with congenital disability) nominated their home as the preferred place to be interviewed and two adult siblings nominated the university. Joining with the siblings

was one of the most important processes in the interview (King, 1994). As time was limited, first impressions were essential to the quality of potential information gained, especially because the siblings had agreed to discuss a private and sensitive issue with a stranger. It was crucial that the researcher appeared trustworthy, sensitive and approachable. The researcher, therefore, included the parents in the joining process (especially with the younger participants), so that a sense of trust could be developed between the researcher and the siblings (Geldard & Geldard, 1998).

Siblings were then interviewed individually in a private room, with the exception of four interviews during which the mothers of the children remained within hearing distance of the interview. Despite requests outlined in the interview protocol to interview siblings in private, the researcher did not insist that parents left the room. However, the researcher confirmed with the siblings that they were comfortable. In all cases, the siblings appeared comfortable to have their parents present, although the presence of a parent was taken into consideration in the analysis of the interview data. When time permitted, siblings from the same family were interviewed on different days to allow the researcher to make observations, write field notes and code the data prior to interviewing the next sibling.

The researcher -- a qualified psychologist -- with experience working with children and adolescents, and experience in naturalistic inquiry, qualitative interviewing and qualitative analysis, conducted all of the interviews. Consistent with Patton's (1990) criteria for judging the credibility of the researcher, the researcher had relevant qualifications, experience and the philosophical perspective necessary to undertake the study in a professional and rigorous manner. The use of one interviewer

across all interviews maximized consistency and familiarization in the data collection and analysis process (Glaser, 1978).

The researcher reminded the siblings about the purpose of the study, the interview process, the importance of their contribution, and their right to withdraw. Siblings were informed that everything they said would remain confidential. However, they were advised that if they revealed any information indicating that they were unsafe or at risk, the researcher had an ethical obligation to report it. They were assured that reporting would not occur without discussion.

Rapport building aimed to minimize the difference in status, knowledge or power that may have existed by the nature of a child-adult and interviewer-interviewee interaction (Grbich, 1999). Siblings were asked questions about school, jobs, hobbies and other interests to assist them to relax and enable the researcher to connect with the siblings. The researcher also explained to the participants her motivation and reasons for conducting the research, which assisted participants in the 'sizing up' process (Grbich, 1999, p.98). This joining and rapport building process created a sense of ease and equality between the researcher and the siblings that encouraged the flow of communication. Rapport building was considered equally important for the adult siblings, some of whom were older than the researcher.

Parents were reminded that the researcher could not provide feedback to the parents concerning their child's answers. It was likely that information given by the children may relate directly to their parents and, if divulged, could negatively impact on the parent/child relationship or parents' expectations of their children. The parents, however, were told that they would be given the general results of the study when completed.

Siblings were reminded that their interview would be audio- recorded as indicated on the consent form. Recording of the interview increased the efficiency and accuracy of data collection, but was conducted discretely and unobtrusively to minimize inhibition of the siblings' responses (Llewellyn, 1996). A flat microphone was usually placed on the floor between the researcher and sibling.

According to Grbich (1999) interviews should be limited to one hour for pre-adolescent and adolescent children. However, participants were free to elaborate and introduce topics of importance to them and therefore, no time restriction was placed on the interviews. The interviews lasted between one hour and two and three-quarter hours, with most averaging just under two hours. Consistent with Lofland and Lofland (1984) and Miles and Huberman (1994), observations made during interviews (siblings, hospital staff, and ICU) and any additional comments or situations that arose were recorded immediately following the interviews. This note-taking ensured that potential bias of the information was minimized because the observations were recorded in detail and were therefore less likely to be distorted by memory. Efforts were made to ensure that the observational data were recorded in descriptive detail with concrete examples to minimize loose interpretation.

Siblings were sent a follow-up letter a few days following the interview, thanking them for their involvement. The researcher's contact telephone number was provided together with numbers for appropriate professionals and resources in the case that they wished to discuss any issues further. All of the siblings interviewed gave their permission to be re-contacted for further participation in the research.

Approximately 18 months after the initial interviews were completed and analyzed, 18 of the 20 siblings of individuals with an ABI, and three of the four adult

siblings of individuals with an ABI were re-contacted (2 siblings from the initial sample and 1 from the adult sample were unavailable for contact). These siblings were presented with the second interview guide developed from the analysis.

All subsequent interviews with siblings were conducted over the telephone and lasted between forty-five minutes and two and half-hours, averaging approximately one and half-hours. Telephone interviews were considered the most cost and time efficient way to re-interview the participants (Wilson, Row & Wright, 1998), especially as good rapport had already been established. According to de Vaus (1991) telephone interviews produce high quality responses.

The siblings were asked to comment on the relevance of the emerging categories and ‘mini-theories’ to their experience. Certain measures were taken to minimize the potential that siblings may have felt obliged to accept the framework, or become intrigued with the conceptualization even if it was not accurate to their experience (Polit & Hungler, 1999). Specifically, siblings were reminded prior to the presentation of the framework that, 1) some or all of the experiences may or may *not* relate to them; 2) that there were no right or wrong answers; 3) that the framework was not a final product of the research, but a part of the on-going analysis; 4) that the researcher was interested in their perspective, including differing points of view to expand the theory. Siblings were asked to identify experiences that did not relate to them. Where siblings’ experience was not reflected in the framework, this data was incorporated into the analysis and helped to explain the theory further (see Theoretical coding, Chapter 4).

All data collected over the telephone were recorded in detail and the information confirmed with the participants at the end of the interview. In addition,

five siblings representing the wide age span of the initial sample were re-contacted on a third occasion to further elaborate and verify aspects of the final theory that is presented in Chapter 5 and 6.

Data collected from parent and physician reports were systematically recorded on a report sheet, in as much detail as could be recalled, immediately following the discussion. It was important that observer accounts were as specific and descriptive as possible to minimize observer interpretation. Consequently, parents and staff were asked to substantiate, with concrete examples, any observations they had made regarding their perception of what siblings' experienced.

Preparation of Data for Analysis

Immediately after each interview, the audiotapes were transcribed verbatim. Consistent with recommendations of King (1994), all interviews were then listened to carefully and notations were made on the transcript regarding nuances of speech, tone of voice, hesitations and other 'paralinguistic' information (King, 1994 p. 25). These notations were included as part of the data for analysis. Each participant was given an identification number to protect privacy and all data was stored in a locked filing cabinet. Identifying and demographic information was stored separately from the interview data.

In addition, each participant was allocated a code indicating his or her identification number (e.g. 03), gender (e.g. ms = male sibling; fs = female sibling) and age at time of the initial interview. This identification system was used during analysis in order to ensure that interpretation of each excerpt remained within its rightful context when the data was coded, separated and added to their respective categories.

Data from siblings of children with congenital disability were similarly coded according to their identification number, gender and age (e.g., 09cfs14 = identification 09, congenital group, female sibling, age 14). Parents (P) and hospital staff (HS) were also coded in a like manner for the purpose of analysis. This system was particularly important given that individual units of data were eventually extracted from the interview for further analysis. Permission was gained from the participants to report their quotes. Names and any other identifying information were changed.⁴

Data collection and analysis occurred over a three and a half year period and continued until the final write up. A detailed model of the sampling and data collection process in this study is outlined in Figure 3.2. The analysis preceding many of the decisions are outlined in Chapter 4.

⁴ To maintain the privacy of the participants, the identification codes were removed following the assessment of this dissertation. Thus, only the participants gender and age at time of interview are referenced alongside their quotes in Chapters 5 and 6.

Figure 3.2. A model depicting the details of the sampling and data collection process utilized in this study.

CHAPTER 4

DATA ANALYSIS

This chapter describes the processes of analysis that transformed approximately 1000 pages of interview transcripts and anecdotal accounts into a comprehensive model of sibling adjustment to their brother or sister's ABI. The purpose of using grounded theory analysis was to discover, from the siblings' point of view, the "core" problem that underpinned the experience of having a brother or sister sustain an ABI, and the processes involved in managing the problem (Glaser, 1978).

This study was guided by the methods of grounded theory as outlined by Glaser (1978; 1998; Glaser & Strauss, 1967). However, the works of Strauss and Corbin (1990; 1998) were also referred to for clarification, particularly for clarification of terms and strategies (e.g. theoretical sampling). Due to the complexity in understanding the application of this method, however, multiple grounded theory studies (e.g. Eaves, 2001; Glaser, 1995; Yee, 2001) were also perused in order to assist with the practical application of the method. The method presented in this study therefore incorporates strategies and tactics from multiple grounded theorists (see Appendix I). Indeed, as Eaves (2001) stated "every researcher who uses the grounded theory method will tend to develop his or her own variations of the technique" (p. 662).

Processes to ensure that the study established trustworthiness (Guba, 1981) throughout data collection and analysis were also applied and will be discussed at the end of this chapter (Lincoln & Guba, 1985; Miles & Huberman, 1984; 1994; Sandelowski; 1986).

Glaser (1978) stated that "the essential relationship between data and theory is a conceptual code" (p. 55). The code is used to conceptualize the underlying pattern

within a set of empirical indicators. Thus, a theory conceptualizes the hypothetical relationships between conceptual codes (categories and concepts), leading to a grounded theory (Glaser, 1978). Grounded theory employs the principles of constant comparative analysis to discover and develop theory from data (see Appendix J for a complete overview of the constant comparative method). The constant comparative approach involves processes of theoretical sampling (see Chapter 3), coding, and integration applied to the data in successive iterations (Glaser, 1978). Memoing is used to facilitate this process (see Appendix K).

Figure 4.1 presents a model of the entire analytic process applied in this study. These processes are presented in a linear format for clarity, but in practice they occur simultaneously as data is re-coded.

Figure 4.1 A model of the recursive analytic process applied in this study.

Open Coding

Open coding involves “running the data open” (Glaser, 1978, p. 56) or, coding the data to ensure full coverage of its theoretical possibilities. Open coding identifies emergent concepts and categories that guide theoretical sampling. All twenty interviews were subjected to open coding.

Glaser (1978) proposed that a thorough analysis and categorization be conducted after each interview. However, according to Yee (2001), this approach,

risk[s] the premature development of the core and near core categories.

Following up on emergent categories too early may lead the researcher down blind alleys. How much can one or two interviews tell you anyway, especially at the start of a project? Central categories are much easier to see when you compare across a wide range of interviews and interviewees (p.17).

The risk of premature foreclosure is particularly high for analysts new to the grounded theory method (Glaser, 1978). Thus, full coding was conducted at the completion of all 20 interviews, although, obvious themes and patterns that were noted throughout interviewing were pursued. The coding rules proposed by Glaser (1978; 1992), and Strauss and Corbin (1998) were then applied to the data.

First, an overall sense of the data was achieved through the conduct and transcription of interviews. Second, each transcript was analyzed one line at a time and excerpts of text (units of data) were coded based on their meaning and perceived significance. Line-by-line analysis was necessary for achieving full theoretical coverage (Strauss & Corbin, 1998; Glaser 1978), as it minimized potential neglect of important units of data that could later elaborate the concepts or categories. Although

not every line was labeled, each was assessed for its potential to describe and add to the emerging concepts. This coding was the first level of conceptualizing the data.

Third, concept labels were placed in the margins of the transcripts next to their respective unit of data. The analyst and two other co-coders (see inter-coder reliability, below) used their own code names to describe the phenomena, usually taken directly from the language of the participants (in-vivo codes), or from psychological constructs that reflected the data.

In accordance with constant comparison, each new unit of data was compared to the labeled concepts using questions such as “*Are these data units referring to the same concept?*” “*How are they different?*” “*Can these data units be coded together?*” “*If not, why not?*” For examples of this first level of conceptualization, see Appendix L.

As coding progressed, similar concepts were grouped together and categories were formed. The formation of categories was aided by asking questions such as, “*What is the underlying meaning of these concepts and their units?*” “*What category or concept (of a category) does this unit of data indicate?*” (Glaser, 1992). In accordance with grounded theory, recursive coding and categorizing decreased the number of categories, yet increased their variability. Names of the concepts and categories sometimes changed with the addition of new data. Transcripts were coded three times in light of the continually emerging concepts and categories.

The units of data were then extracted from the transcripts and grouped into separate files according to their concepts and categories. Units of data were assigned to as many concepts and categories as possible “to preserve subtle nuances of the data” (Rennie, Phillips & Quartaro, 1995, p. 148). This process of open categorization

(Glaser, 1978; Rennie et al., 1995) is what separates grounded theory from content analysis where units of data belong to one category only. When no new categories emerged, data from the adult siblings were sampled and coded in order to extend the existing concepts and categories. Therefore, through the process of open coding, categories were developed, verified, modified and saturated through recursive analysis - “going over and over the data” (Glaser, 1978, p.61).

Theoretical Coding

Theoretical coding involves the conceptualization of how categories and their properties are linked or related to each other. These links become hypotheses that are integrated into the theory (Glaser, 1978). Glaser (1978) provided a list of eighteen types of theoretical codes (e.g. causes, consequences, strategies, contexts, contingencies, process, degrees, types, models, etc.) and advised that prior to coding, analysts become sensitive to the ways in which categories could be related (see Glaser, 1978 for a detailed review of theoretical coding).

Theoretical codes included substantive codes or conceptualizations about how categories and their properties linked. To assist this process, questions were asked of the categories, such as, “*what conditions need to be present for this concept or category to arise?*” “*To what degree?*” “*Upon which contingencies does this category depend?*” Once again, through recursive analysis, links in the categories began to emerge. These links were memoed and mini-processes were developed.

These mini-theories formed the guide used in the second wave of interviews (see Chapter 3; Appendix D). As described in Chapter 3, questions presented to the siblings in the second interviews were focused on these mini-theories and their

integration. The interviews aimed to expand and verify the emerging categories and mini-theories and further integrate them. Additional questions and themes that emerged throughout these interviews were explored, in accordance with theoretical sampling.

Following constant comparative analyses of the new data, the mini-theories were integrated, organized, expanded and subsumed under two higher-order categories – *vulnerability* and *sacrificing*. The higher-order category, *sacrificing*, along with the categories and sub-categories that it subsumed, appeared to depict the strategies that siblings employed to combat or manage *vulnerability*. At this stage, it was assumed that *sacrificing* and *vulnerability* were core categories because they linked and integrated most concepts. However, there were still concepts (e.g., *withdrawal* and *fighting the injustice*) that did not fit these emerging categories, indicating that the theory was not yet fully developed. Since the aim was a parsimonious theory with the power to explain all the data, the theory thus needed further analysis.

Identifying the Basic Psychosocial Problem and Basic Psychosocial Process

Glaser (1978) suggested that a theory be limited to one core category. For a category to be judged as core, it should relate to as many other categories as possible, account for variation in a pattern of behavior (whether varying in type or degree), reoccur frequently in the data, and logically link and integrate the categories in terms of their causes, consequences, context, contingencies, covariance's and conditions (Fagerhaugh, 1995; Glaser, 1978). Therefore, further memoing and analysis was conducted in an attempt to raise the conceptual level of the categories. An abstract core category that accounted for variability in the data was discovered by re-analyzing all concepts and categories, and by asking questions such as, "*What purpose does*

sacrificing serve?” “Does it always happen? Why/why not?” “What process is underlying all the mini processes?” “What is the underlying meaning and purpose of these categories and their properties?” “Is there an underlying link between vulnerability and sacrifice, and other categories that seem unrelated?” “Do categories that appear to differ from sacrificing serve a similar purpose?” “What is the aim of these categories collectively?” “How do they relate to each other? Why?” Eventually, through recursive analysis with these questions in mind, a basic psychosocial process that linked and integrated all of the concepts and categories -- even categories that seemed unrelated initially -- emerged.

A basic psychosocial (BPS) *process* is one type of core category that explicates and accounts for change that occurs over time, remaining intact even when conditions vary (Fagerhaugh, 1995). Another characteristic of a BPS process is that it resolves a BPS *problem*. A BPS problem is defined as a problem shared by participants, but not necessarily articulated by them (Hutchinson, 1986).

In this study, the BPS problem for siblings was *losing equilibrium*, which included the category, *vulnerability* and its concepts. The BPS process, *regaining equilibrium*, was associated with the management of the BPS problem. The BPS process subsumed the category *sacrificing*, and other categories that initially appeared unrelated (e.g., *withdrawal*, see Chapter 6), but which all aimed to resolve the problem. The degree to which siblings engaged in the BPS process appeared to be dependent on the degree of disequilibrium they experienced. Thus, the BPS problem explicated the conditions and contingencies that influenced the process of regaining equilibrium. Examples of the analysis process (e.g., coding, memoing) in the development of the BPS process are illustrated in Appendix M.

Selective Coding

Selective coding involved analyzing and coding data in terms of how it was associated with the BPS process and problem only. Thus, new data (e.g. siblings of children with congenital disability, parental data, hospital data, literature) was coded in light of extending the conditions and boundaries of the BPS process and problem. This “new data” included both fresh interview data and data already coded but re-analyzed through a new perspective or understanding (Strauss & Corbin, 1998). Thus, data collected and analyzed from the 20 interviews with child and adolescent siblings of people with an ABI was re-coded in light of new insights missed in earlier stages of the analysis.

In summary, through the processes described above, hundreds of codes were subsumed under a smaller number of concepts. These concepts were subsequently subsumed under an even smaller number of categories. These categories became the properties of a BPS process that linked and integrated all of the concepts and categories and accounted for variability in the data. The BPS problem and BPS process identified in this study are described in Chapters 5 and 6 respectively.

Evaluating Qualitative Research: Establishing Trustworthiness

Scientific rigor and the integrity of a theoretical framework are critical to *both* quantitative and qualitative research (Patton, 1990; Rich & Ginsburg, 1999). Indeed, a central concern of this study was to transform and interpret the data as rigorously as possible. It is essential, however, that qualitative research is not judged against quantitative criteria. As stated by Lincoln and Guba (1985) “criteria defined by one perspective may not be appropriate for judging actions taken from another

perspective...” (p. 293). Thus, Lincoln and Guba (1985) proposed alternative criteria for judging qualitative enquiry. They claimed that to establish trustworthiness in qualitative enquiry, the quantitative principles of “internal validity”, “external validity”, “reliability”, and “objectivity” be replaced with more appropriate terms, such as, “credibility”, “transferability”, “dependability” and “confirmability”. Lincoln and Guba (1985) further recommended prolonged engagement with the research participants. The application of such criteria to this study will now be discussed.

Credibility

To increase the credibility of qualitative findings, Lincoln and Guba (1985) proposed the use of multiple and credible interview respondents and methods (*triangulation* and *sample credibility*), multiple coders and peer debriefing (*inter-coder reliability*), member checks and negative case analysis (*member-checking*).

Triangulation and Sample Credibility

The utilization of multiple interview sources (e.g. child, adolescent and adult siblings of people with an ABI, child and adolescent siblings of children with congenital disability, parents, and hospital staff), and data collection methods in this study (e.g. interviews, observations, multiple interviews) was described in Chapter 3. Triangulation of data methods and sources contributes significantly to the credibility of the findings (Miles & Huberman, 1984; Patton, 1990). Triangulation “overcomes the deficiencies and biases that stem from any single method” (Mitchel, 1986, p.19) because it enhances variability in the data, and permits themes to be confirmed by a variety of sources. Indeed, the data sources in this study varied considerably both

between and within groups. Unlike the conventional aim of triangulation to find evidence to confirm categories, however, this study aimed to identify and integrate disconfirmatory evidence, until the categories confirmed the data. Indeed, Yee (2001) highlighted that “the so-called aberrant accounts are often the most revealing” (p. 9). Thus, triangulation of data sources and methods increased the breadth, depth, and variability of the data, which ultimately increased the applicability and transferability of the theory.

In order to establish a credible sample, the sample sources were selected on the capacity to meet all criteria checks for ensuring reliability and representativeness as suggested by Miles and Huberman (1994, p. 34) and Strauss and Corbin (1998). Specifically, the study sample 1) was relevant to the area of research; 2) provided opportunity for the phenomena under study to appear through interviewing; 3) had conceptual power and representativeness; 4) produced data detailing personal accounts of experience; 5) was feasible in terms of access, resources and researcher experience; and 6) was ethical.

In addition, this study met the criteria of adequacy and appropriateness as proposed by Morse (1994). Adequacy refers to the amount of data collected rather than the number of subjects, and is attained when sufficient data have been collected so that variation is accounted for and understood. In this study, adequacy was evidenced by the collection of data until the categories became saturated. Saturation was achieved when the categories explained and accounted for variability.

Appropriateness refers to the selection of information according to the needs of the study and emerging model, from multiple data sources (Morse, 1994). Indeed

appropriateness was evidenced by the application of theoretical sampling (see Chapter 3) and triangulation of data sources and methods.

Inter-Coder Reliability

The presence of three coders provided a means of numerically assessing the reliability of the analysis. Coder-triangulation (Patton, 1990) ensured that conceptual decisions were true to the data, and that concept development and abstract conceptualizations were not based on researcher bias or any non-reflective, a priori theories. As prior knowledge of related literature increases the risk that coding may yield pre-conceived categories (Glaser & Strauss, 1967), the inclusion of two coders not cognizant with the literature ensured that interpretation of the data by the primary researcher was void of bias (Rennie et al., 1995). The use of multiple coders also provided multiple perspectives on the data. Further, multiple coding increases the likelihood that discrepancies between data and concepts will be highlighted in the early stages of analysis (Glaser, 1978; Strauss & Corbin, 1998).

Seven of the initial twenty interviews (i.e., approximately one-third) were independently open coded by all three coders. These transcripts were chosen to represent each gender as well as different ages and time since injury. The primary analyst coded the remaining thirteen transcripts and all additional data alone. After coding each transcript independently, the coders met to examine the codes and identify agreements and disagreements. Disagreements included excerpts of text coded by one coder but not by the others, or coded differently by those coders on the meaning of specific excerpts.

In accordance with Weber's (1990) suggestion, inter-rater reliability was calculated prior to resolving any disagreements and discrepancies between coders. Given that analysis was an on-going process and no finite number of items could be calculated, it was not possible to use statistical methods of calculating reliability, such as Cohen's (1960) kappa coefficient. Accordingly, Miles and Huberman's (1994) simple percentage method of reliability calculation was utilized.

$$\text{Percent agreement} = \frac{\text{Number of agreements}}{\text{Number of agreements} + \text{Number of disagreements}} \times 100$$

(Reliability)

Open coding resulted in inter-rater reliability that ranged from 89.7% in the initial inter-rater coding session to 100% by the final session. The average reliability measure was 93.1%. Miles and Huberman (1994) claimed that inter-rater coding does not usually reach higher than 70% in initial cases but should reach at least 90% after repeat checking. Consequently, the coding process was considered to be highly reliable and the concepts being generated were considered to be true to the data.

Any disagreements were discussed to reach agreement. The agreed definitions became a reference for further coding, although they continued to evolve during the subsequent analysis. All twenty interviews (purposive sample) and subsequent interviews were reanalyzed using these definitions. Checking occurred at random points during the remainder of the analysis.

Member Checking

According to Glaser (1978), participants should be able to immediately confirm the accuracy and validity of the findings as well as offer feedback to confirm or

disconfirm the model. As illustrated above, siblings were contacted throughout the analysis process, some on three occasions, to verify and extend the emerging framework. Siblings presented with the final theory described in Chapters 5 and 6 were asked to comment on the relevance of the framework to their experience. This form of member checking is essential in order to establish the credibility of the research findings (Lincoln & Guba, 1985). Member checking specifically sought to identify negative cases and address the possibility of the “holistic fallacy” (Sandelowski, 1986, p. 32), one of the major threats to credibility in qualitative research.

Member checking provided confirmation of the theory by the most important judges, the participants. None of the siblings in this study dismissed the theory. The following comments were recorded from the member checks. *“You’ve really captured the experience”*; *“It’s nice to know other people feel the same way I do”*; *“Are you reading my mind?”*; *“You have all these feelings and it’s nice to have them clarified”*. Similar feedback was received following the presentation of these results at specialist ABI conferences and to family members of people with an ABI.

Transferability

Although qualitative research does not aim to deliver external validity of an inquiry, it can provide the thick description necessary to enable individuals to transfer the findings to their own experience (Lincoln & Guba, 1985). Thus, transferability as opposed to generalizability is the aim of qualitative enquiry. According to Strauss and Corbin (1990), the transferability of a grounded theory is achieved through the process of abstraction that evolves throughout the course of data collection and analysis. They

stated that “the more abstract the concepts, and more variation uncovered in the original study, the more likely it is that the propositions apply [or are transferable] to a broad range of situations” (Strauss & Corbin, 1990, p. 15).

Indeed, a BPS process that accounted for variability across a range of data sources, such as child, adolescent and adult siblings of people with an ABI and siblings of children with congenital disability, was developed in the current study. Thus, although the current study provides a specific and in-depth account of the experiences of siblings of children with an ABI, it is likely to be sufficiently abstract to enable its application to other groups (e.g. siblings of children with illness or congenital disability).

Dependability and Confirmability

Dependability and confirmability relate to the transparency of the methodological process and how well the data, findings, interpretations and recommendations are supported by the data (Lincoln & Guba, 1985). Methodological assumptions and procedures in qualitative research are often inadequately described, usually due to the need to describe a multi-faceted, cyclical and complex process in a linear format (Swanson-Kauffman, 1986). However, Sandelowski (1986) emphasized that rigor in qualitative research will only be achieved if researchers clearly describe and justify what was done at each step in the study, in a document that is referred to as an audit trail (see Lincoln & Guba, 1985). The inclusion of such a document was not possible due to its size. Instead, the methodological procedures and processes conducted have been detailed and described as explicitly as possible throughout this dissertation, particularly Chapters 3 and 4.

The methods of data collection employed in this study satisfied the criteria for establishing trustworthiness as proposed by Lincoln and Guba (1985) and Sandelowski (1986). Specifically, the study was credible in that it applied the principles of triangulation, sample credibility, inter-coder reliability, member checking and negative case analysis. The study was also transferable as indicated by its ability to identify a core theme that accounted for variation in the data. Finally, sufficient detail of the methods employed was provided to ensure that the study met the criteria of dependability and confirmability.

The Theory Write-up

The following chapter details the grounded theory developed from the methods of data collection and analysis presented above. The theory presented is one possible account to explain the data, and thus should be considered emergent and tentative. The theoretical processes should be imagined on a continuum with some people experiencing them more consistently than others (Glaser, 1992).

The categories pertaining to the BPS problem and BPS process and the sub-categories that represent them are identified by the main headings. Concepts that represent the sub-categories are italicized. Codes that characterize the concepts and categories are integrated throughout the write-up. Concepts are italicized for ease of identification and to clarify and emphasize links between categories, sub-categories and concepts. Quotes from the data assist to illustrate the categories and concepts described.

CHAPTER 5

RESULTS

Losing Equilibrium: ABI as a Life-changing Event

Having a brother or sister sustain an ABI was a life-altering event for siblings. This unexpected tragedy was associated with permanent changes that infiltrated every aspect of the siblings' lives. Denzin (1989, p. 17) described such an event as a major "epiphany" -- an interactional situation of crisis that leaves marks on people's lives and has the potential to create "transformational experiences" (p. 15). Indeed, an ABI was a "turning point" (Strauss, 1959) that, once experienced, had a permanent impact on the siblings because their worlds were never again the same.

In my family now our timeline ... is before and after Rick's accident. That's sort of a demarcation line because....your experiences in life and how you interact with life and other people changes after an incident like that (fs20).

Siblings experienced major changes in themselves, their family and environment as a result of their brother or sisters' ABI. One sibling explained,

...the whole situation ... sort of turned our lives upside down which was a real bugger. Probably because everything was going really smoothly and then, Yuk....lots more stress than usual....[We were] tired and freaked out and all that sort of stuff that you have got to expect (fs16).

Another sibling concurred,

The whole family just changed automatically. It was really weird....quick change....It all happens at once and then it all stops....you so quickly adapt to it because you don't have time to think... (ms14).

Although the impact of a sibling's ABI was sudden, the consequent changes and losses were non-finite. "When it first happened it was very hard, sometimes it's still very hard ... [Eight years later] ... that still is a big thing in my life" (ms13). In

fact, the changes and losses were still strongly expressed, even up to twenty years post injury, as evidenced by the adult siblings. The impact of an ABI on siblings was akin to a “psychosocial transition” as defined by Parkes (1988). Such transitions usually occur over a short time period with little opportunity for preparation, have lasting implications, and require people to revise their assumptions about the world (Parkes, 1988). Indeed, an ABI presented loss and change for siblings, requiring them to make internal and external adjustments.

This chapter describes the loss of equilibrium that siblings experienced as a result of an ABI. Specifically, siblings were exposed to a series of events and conditions that threatened their sense of security, safety, and control. Their lives were dominated by a sense of environmental and emotional loss of equilibrium. *Losing Equilibrium* emerged as the basic psychosocial (BPS) problem for siblings (see Chapter 4) and was defined by the concepts of *vulnerability* and *emotional turmoil* as outlined below. Chapter 6 outlines the basic psychosocial (BPS) process, *regaining equilibrium*, that siblings employed to manage the problem of disequilibrium in their lives. Although concepts that form these processes below are presented separately for the purpose of clarity, they are often interrelated and occur simultaneously. Figure 6.1 outlines these processes in their entirety.

Losing Environmental Equilibrium: Vulnerability of the Assumptive World

As described above, an ABI occurred suddenly and unexpectedly, exposing siblings to a series of life-altering experiences from which most children are usually protected. Many siblings witnessed their brother or sister sustain an ABI and were exposed to the possibility of death. These experiences robbed siblings of their

childhood naiveté and confronted them with the vulnerability and unpredictability of life. Exposure to these conditions was traumatic for siblings, but just as traumatic was realizing the vulnerability of their assumptive world.

The term *assumptive world* was coined by Parkes (1971; 1975) to conceptualize individuals' subjective view of reality. The assumptive world represents a framework of expectations, beliefs, and anticipations about how the world should be (Bruce & Schultz, 2001; Parkes, 1988). Assumptive worlds are constructed from individuals' experiences and interactions with their environment (e.g. parents and siblings) to form personal patterns that provide familiarity, predictability and a sense of safety. Through the process of socialization, the familiar becomes *the world that should be* and translates into a reality that is taken for granted (Bruce & Schultz, 2001).

ABI confronted siblings with the vulnerability and fragility of their assumptive worlds, resulting in a sense of personal insecurity and disequilibrium. Specifically, siblings were exposed to a variety of conditions created by an ABI, which forced them to redefine their place in the world. Exposure to these conditions, namely, *exposure to the unforeseen*, *exposure to mortality*, *enduring exposure to the familiar stranger*, and *exposure to the vulnerability of the family unit*, although some of them transient, had long-lasting consequences as discussed below.

Exposure to the Unforeseen

Witnessing the onset of their brother or sister's ABI was the first of many events that placed in doubt the safety and predictability of the world for siblings. Several siblings witnessed their brother or sister being injured (e.g., falling from a bike,

tree or car, suffering an aneurysm, near drowning, being hit by a car, or were in a car accident with their injured sibling).

Witnessing such an event was described as a “nightmare,” a traumatic, terrifying, frightening, confusing and surreal experience for the siblings, who were able to vividly recall the incident, even up to seven years post-injury. As illustrated in the examples below, ABI often occurred during the siblings’ play or everyday activities, heightening the unexpected nature of the event and resulting in a greater sense of unpredictability. Witnessing the accident confronted siblings with mortality, with many believing that their brother or sister was dead. Some were even placed in a position of responsibility to assist their injured sibling following their injury. One eleven-year-old, who was nine at the time, described running for help after his sister fell from her bike in front of him.

[It was] very scary ... [I was] horrified. Really, really scared like bad nightmares and that, and I thought I was never going to wake up, but I did wake up because I was awake already. But I felt like that because I was just so scared and it felt like I couldn’t run fast enough to get home. I thought that by the time I got back she was going to be dead (ms11).

Another thirteen-year-old sibling recalled seeing his brother’s fall while they were playing together seven years earlier.

He was [swinging] and just lets go of the rope and sort of flips ... head first, at some force, and then he just lay there ... I was freaked....I started shaking him and then I dragged him over to the front steps there and he had a bit of a bleed from the back of his head, and I ran inside and [shouted] ‘Mum, mum Tim’s dead!’ Because I thought he was dead, I didn’t really know (ms13).

An eleven-year-old participant in the following example was involved in a bus accident with her brother.

I wasn't actually watching the road at the time, I was reading a book. But the impact gave me a shock and then I turned around and looked at my brother and he was unconscious and blood was streaming down the side of the seat. Then I was screaming and the bus driver was going, 'It's okay, it's okay.' And I was going, 'It's not, it's not...' I thought he was dead....[The] ambulance came and me and Russell had to go in the same ambulance....He was screaming, just hearing him scream and the ambulance siren going you know at the same time was just like 'Oh my God! What's going to happen?' [It was] scary (fs12).

Even for older siblings, the time was terrifying and confronting, as described by a sixteen-year-old girl who saw her sister fall from a dirt bike.

She just went ... for a bit of a ride, and I had this feeling like something was going to happen and she hit something like a rock or some dirt rock, and she was flat on her face. So I am there screaming and I ran down to her and [my other sibling] was there and I said 'Go get mum, go get mum!' ... I said, 'C'mon Stephanie you are not dying' because she was sort of moaning and moving around a bit, then I sort of realized she was out of it. That totally freaked me out and I went to get mum....So I was there crying my little heart out ... half of it was in a big confusion....We had to try to keep her head still, which was virtually impossible because she was flinging around like there's no end. [She was] really strong. Trying to hold her down wasn't easy....After millions of years the ambulance turned up ... it was horrible....Like thinking of the accident, like I don't want to see it again because I saw it ... I can make myself do it, like I can visualize it again which I don't want to do, because I don't want it to happen again (fs16).

Siblings who witnessed their brother or sister in less dramatic situations, such as having an aneurysm, also recalled being scared and confused, as described by one fourteen-year-old,

I'm lucky that I was there that day because I'm the one that, like, he sort of called mum, and he was lying on his bed and he was ... going crazy and it was really scary. And, like, my mum didn't hear it so if I wasn't there I don't know what could have happened ... he was lying on his bed 'cause he had a headache and then he started vomiting in his bed. He called us and we didn't know what to do....It was panicked and scary (fs14).

Witnessing such an event was so profound and traumatic that many of the siblings experienced symptoms similar to that of post-traumatic stress disorder (PTSD). Although differing in degree, all siblings who witnessed their brother or sister's injury still experienced visual or auditory memories of the accident many years later. Others described intrusive thoughts and flashbacks related to some aspects of the experience that endured from weeks to several years post-injury.

The front of the car hit her, she has gone up, tumbled and then she has landed on the top of the windscreen and gone up again and then landed about twenty feet down the road....So I had that in my head and that was pretty much it....The first few weeks I just had the thing of seeing her get hit by the car go through my head like ninety percent of the time (ms18).

Seeing their brother or sister being hit by a car also gave many siblings nightmares that continued for years "Bad, I dreamed, and that was bad....The way Barry got hit by the car and the screaming brakes..." (ms13). One sibling described how seven years later he still experienced flashbacks. "It was scary, yeah daunting, it still comes back and you still think about it and you still feel it....[The accident] comes back in black and white all the time" (ms13). The memories and flash backs were constant reminders of what happened and what could happen again. Some participants even described how their stress related to witnessing the accident increased with time due to their increased understanding of the situation and the possible results. "It gets worse as time goes on because you understand it more" (ms14). The more understanding siblings had of the event, the more they realized the vulnerability the situation presented and the more aware they became of the fragility of life.

Siblings did not have to witness the accident to be exposed to the trauma of an ABI. Some siblings heard the accident occurring and were not allowed access to the

scene, while others were exposed to the event through story telling, photographs of crumbled cars and others' recall of the event. These siblings were just as traumatized, some even experiencing disturbing nightmares and concerns about the event, despite not witnessing it. These siblings used the powerful force of their magical thinking (Geldard & Geldard, 1998) to envisage an event just as traumatic as if they had witnessed it firsthand.

Underlying the trauma of this event was the message that siblings and their family were not immune from random events or tragedy. One sibling described, "It was really scary, you never think about things like that happening to you" (fs20), while another sibling recalled, "[I wondered] if he was going to make it, and not thinking for a second that he is not because this stuff never happens to you, you know, you never think it does" (ms17). Siblings' previous schema of their assumptive world was questioned by exposure to such an event, which resulted in a sense of unpredictability that extended and was generalized to their childhood play and everyday activities. This concept is illustrated in the following example from an eleven-year-old male sibling.

Sibling (11 year-old male): I wasn't really expecting [the accident] to happen, I just thought it was going to be a fun day and now it seems that when I go down a hill now, or I am just riding around everywhere, it's sort of like, what ever [will] happen? It can ... be really bad, even though you are having a lot of fun....But yeah that's really all the thoughts that have changed.

Researcher: So do you find that sometimes even when you are having a lot of fun there's a little thought that pops into your mind like 'oh what if something happens?'

Sibling: [Nods] Like on the Tower of Terror, like when I go on the Tower of Terror....It's really fun, but when I go on [it], I am sometimes scared - that maybe if Dreamworld had a blackout, then the Tower of Terror would crash ... that sort of scares me a bit....I sort of think they would have generators and everything on but that sort of scares me, things like that....And ... from just walking around when its raining, if I am near anything or just because I am standing up, like it might attract lightening...

Researcher: Did you used think these sorts of things before Tammy's injury?

Sibling: Not as much....Still think it but not as much, not as near as much.

Researcher: Okay, so do you think about things like that quite a lot?

Sibling: Yeah, the big hill in [Burkville], I have been down that heaps and heaps of times and I thought yeah that's safe, but I don't think that's really safe now.

Although most of the siblings said that with time they thought and dreamed about the event less, the impact of this tragedy and its messages were long-lived, and the experience firmly integrated into their memory where it was periodically revisited

Exposure to Mortality

The hospital environment exposed siblings to a variety of conditions that further threatened their safe and predictable worlds. Siblings who were exposed to the intensive care unit (ICU) described feeling shocked, scared and confused about the medical equipment attached to their brother or sister and the fact that they were unconscious and unresponsive. "...He looked so ugly, he was just white and he had all tubes coming out of every crevice of his body" (ms13). Exposure to these conditions were traumatic for siblings who had never before seen medical equipment. The emergency hospital scene carried with it messages of panic, illness and death as illustrated by an eleven-year-old.

She was in intensive care and she had heaps of pipes going down her throat and the breathing [equipment was] beeping....Then she threw up and all the pipes went all down and started beeping more and heaps of doctors came over, it really scared me. Then we went out, I went to look outside and I didn't get to see very much of her for a while then because I didn't really want to... (ms11).

Exposure to these conditions intensified the siblings' fear because it was foreign and clinical. Many siblings at this point realized the seriousness of their brother or sister's condition and their vulnerable predicament.

The thought didn't come into my mind that something would happen to him, and then they took me down to see him in intensive care ... I just started crying and I broke down in front of him. Just seeing him with all those tubes in him ... I woke up a bit and thought ... I hope he gets out (ms17).

Siblings' greatest fears were actualized when they were informed, usually by parents and/or doctors, that their brother or sister may die. Several siblings, however, simply overheard this news. "I have got big ears and I listen in" (ms13). Siblings who were involved in this stage of their brother or sister's recovery process recalled strong feelings and vivid memories about their sibling's fight for life. One sibling recalled, "The doctors used to say 'Ah, don't be surprised if he is not alive tomorrow' ... because he was really bad" (ms15). Similarly, seven years post-injury, another sibling recalled the negative prognosis presented to his family, "the neurosurgeon said that he had no chance and that he was going to die today or tomorrow, and if he did make it through he'd be a vegetable..." (ms13). The fear of losing their brother or sister and the vulnerability of the situation was also reinforced by dismal statistics.

My parents [were told that] as soon as anyone walks into this they have a twenty percent chance of dying ... I was just scared, I mean I just wanted my brother back ... I mean if he just woke up ... just if he would talk to me or [if I could] see him show a bit of life ... it's really scary (ms17).

Confronting the possible mortality of a family member, often for the first time, was overwhelming and frightening. "...[We were] told that she [injured sibling] was going to die two or three times....I just got really scared that Mary was going to die, I've never seen anyone die" (ms11). Siblings felt an overwhelming sense of helplessness, hopelessness, and loss of control, "...it was like, you know when you are on a swing and your stomach just goes, that sort of feeling. As soon as I saw him [I thought] there's no way he is going to come out of here" (fs20).

Ultimately, the potential death or disability of their brother or sister threatened the siblings' assumptive world. Their world, that was safe and predictable, became vulnerable and unpredictable, generating a fear of what lay ahead. To siblings, an ABI was synonymous with what Bruce and Schultz (2001) called a "dreaded event" (p. 9), that carried with it connotations of helplessness, abandonment, and dependency learned through story telling and media. ABI activated fears associated with "dreaded events" that forced siblings to contemplate a future outside of their expectations.

I was worried about her heaps....What she was going to turn out like after it -- [Did] she have bad brain damage? Or, what's going to happen?...Is she going to be the same with me? Cause ... me and her were really close ... I would talk to her about anything, I was mainly worried about how she would turn out after it (ms18).

Another sibling who was seventeen at the time her brother was critically ill said, "I thought of going to Rick's funeral and [thought] how would I cope not having this person in my life?" (fs20). The sense of vulnerability that resulted from exposure to the near death of their injured sibling, however, was not confined to the acute hospital stage. The enduring nature of the ABI sequelae continually exposed siblings to their injured sibling's ongoing vulnerability.

Enduring Exposure to the Familiar Stranger

Once their injured sibling was back home, siblings were faced with another set of conditions and challenges as a result of their brother or sister's persisting disability. The fact that their brother or sister had changed psychologically, emotionally, behaviorally and/or physically further undermined the siblings' previously safe and predictable world. Siblings were expecting that, because their brother or sister looked the same as they did prior to the injury, they would behave the same. "She just

changed totally....I just used to get upset at her. Like, sometimes I would think ‘far out! She’s not the same’” (ms18).

For many siblings, their injured brother or sister seemed like a *familiar stranger*. “My brother ... is not himself, he’s had a total different personality change” (ms17), and “He wasn’t like the same because he had changed really personality wise ... he wasn’t Sean anymore...” (ms14). Several siblings noted the subtlety of these changes and the fact that they had to get to know their brother or sister again.

To me he is a totally different person, but everyone else says, ‘he’s alright, he’s alright, yeah he’s not bad’....everyone else says, ‘yeah he’s good, he’s good’ ... but no where near my Blair, like the one [I knew]....Yeah like I have been with him for sixteen years, I know every little thing that he does and you pick up on it [the change] pretty quickly (ms17).

Even when siblings became accustomed to the changes in their brother or sister, however, they still experienced *unpredictability* and uncertainty regarding their behavior, prolonging exposure to vulnerability in their worlds for many years post-injury.

There’s always new little things ... that the head injury had given him....It’s all small things that change along the way that you have to prepare yourself for... (ms13).

Many siblings described their injured brother or sister as unpredictable and, at times, dangerous. Their erratic and variable behavior was confusing and difficult for siblings to understand. Siblings commonly described personality and behavioral changes that made little sense to them. For example, one sibling said of his sister, “like, for instance she is really [rude] now, for some reason she is just [rude]” (ms18). It was common for siblings to describe their injured sibling, even if they were older, as being inflexible, less mature, and less tactful after an ABI. They described that they

had difficulty predicting their injured siblings' behavior, which often seemed puerile and untrustworthy.

It's hard, very hard....You get some good times. But, you've got to be careful because at the same time she will get you into trouble....You don't know what she can do. You just can't trust her 100% yet (ms18).

For some participants, their injured sibling's erratic and unpredictable behavior represented serious threats to their lives and those of their family members, further jeopardizing the safety and security in their world. This violent behavior had a profound impact on the siblings who described that suicide threats and violent outbursts had become a part of their lives. For example, one participant said of his brother,

He went through a stage where he was just on a murder spree, he wanted to kill himself ... like, he has tried ... to strangle himself, tries to run away from home and that, it does get hard, and there are hard moments and that....Sometimes he hates us but sometimes he doesn't....And he gets like really angry with us every now and again and like tries to kill himself and that and it's just you know, you've got to live through it....The last year or so he has got a lot better and he's saner....He's just got no fear, no fear at all and I don't know why (ms13).

Other siblings recalled similar stories that were equally serious. "He was threatening to kill us and things like that....and I would sleep with my parents most nights ... it was pretty upsetting..." (ms14). Siblings said that their brother or sister's changes were felt in their everyday interactions where typical sibling conflict was misinterpreted and became violent. "[He is always] annoying me, bangs his head, he head butts, and he is always angry at everybody..." (ms13), or "sometimes it's bad because he gets angry very quickly" (ms12). The injured child's unpredictability often

made siblings feel like they were walking on eggshells and they were consequently wary to be around them.

He'll get mad at me, or hit me or something and it can be scary at times....And if I take something out on him ... oh, like, he'll just, I don't know, he is really mean when he wants to be. You have to be careful around him, sort of thing. I don't know, one minute ... one day, we can be really getting along really, really well, for brother and sister anyway, and then next minute you know he can be getting mad at you for something that you didn't do or whatever (fs14).

Another issue that added to siblings' sense of instability, unpredictability and vulnerability was their injured sibling's apparent emotional lability, depression and moodiness, that increased since the ABI. "Like just ever since he got sick ... his moods sort of changed..." (fs14). Several siblings were able to confirm their stories by showing the holes punched in walls of their houses or other breakages.

He is always in a bad mood ... that goes for school, friends, he has a couple of friends but he doesn't talk to them anymore. Activities he doesn't do any and so on, he is always crying....He is always throwing stuff around (ms14).

Attempted suicide and suicide ideation highlighted the seriousness of the injured child's vulnerable emotions, reinforcing the siblings' sense that their future was unpredictable.

The big case about it is that [he] gets depressed a lot because he can't do what he used to do....He can't play basketball and do stupid stuff ... [So there's the chance of] him going off and doing something stupid because he is depressed about not having much work and shit (ms17).

Further prolonging exposure to vulnerability and disequilibrium was siblings' perception that their injured sibling's physical health was interminably fragile. Although some of the injured siblings were more physically fragile than others since the accident, even those who recovered to a high level of functioning were still perceived as vulnerable, "I don't like it when he's vomiting or anything because he

might choke, hurt himself somehow” (fs13). Similarly, a sibling who was an infant when her brother sustained an ABI, ten-years earlier, said, “he has already got hit by a car once and he nearly died and if he gets hit by another car he could die” (fs10).

Seizures, falls, headaches, dizzy spells and other symptoms resulting from an ABI continually reminded siblings of ongoing vulnerability of their injured brother or sister. After 17 years, one adult sibling reported that his brother’s fragility and vulnerable health condition continued to worry him for many years.

I used to worry a lot that he was going to die, when I was younger, [I thought] he is only going to be here for a couple of years and then he is going to die....Imagine being a kid and thinking well my brother is going to be dead any minute, it’s pretty difficult....But other than that [I] just worry about him having a fit or something because then he is in hospital and he could potentially die....It’s that grief thing that you can’t breathe again (ms26).

Siblings noted that deviation from daily routines and disruption caused by changing life events, contributed to fluctuations in their injured sibling's behavior. Thus, regardless of the degree of exposure siblings had to the onset of an ABI and the associated hospital experience, the non-finite, unpredictable, and fragile nature of the ABI sequelae continually reinforced a sense that their injured brother or sister was vulnerable to re-injury or death, even many years post injury.

Exposure to Vulnerability of the Family Unit

In addition to being exposed to the onset of an ABI and its surrounding traumatic and confronting experiences, siblings experienced a loss of familiarity and stability in their family environment. A child’s ABI resulted in many sudden changes to the family routine, including a loss of parents’ emotional and physical availability. Although parental support and assurance can quell children’s anxieties in the face of

threat (Bruce & Schultz, 2001), for many siblings in this study, parents were not available to undertake this role. Understandably, in the initial period following the onset of an ABI, parents were worried and their energy was focused on the injured child. As a result, siblings experienced an *absence of parental attention*, which became a perception of on-going *differential treatment*. Siblings also observed *family turmoil* and *parental vulnerability* within their home environment. These changed life conditions added further challenges to the siblings' worlds, enhancing their sense of vulnerability and loss of equilibrium.

Absent Parents

Following their brother or sister's ABI, siblings often had very little physical or emotional contact with their parents, especially while their sibling was still in hospital. In referring to this time, siblings echoed experiences such as "...my mum was only home from late at night to early in the morning and then she would leave again -- go up to the hospital with Jerry....She was up at the hospital everyday with Jerry" (fs14). Siblings who were young and dependent at the time of the ABI, vividly recalled being separated from their parents, particularly when no explanation was provided for this separation. Siblings were confused and scared, and their sense of security in their parents' ability to protect them was lost.

I was only young and mum would stay up at the hospital ... it was kind of hard because we didn't see mum for ages....[I] was scared I suppose, you know dad just left ... and we didn't know what was happening....confused I think ... why it happened and ... why wasn't mum coming home? (fs14).

The decreased sense of security was exacerbated for some siblings by the need to be relocated to relatives or friends in the absence of their parents. "I really missed having

mum or dad, Rick or Riley, and I was just on my [own], it was just me and relatives who I thought ... don't really know what it is like" (fs20). Siblings felt displaced and abandoned.

Well I was only young and like mum would stay up at the hospital so we would have to drive up, and we didn't see her for like ages and dad would like drive back down and see us. But, for like a while my auntie looked after us so....Yeah so it was like I suppose we were young....But it was kind of hard because like we didn't see mum for ages....because she stayed up there like all night and day as well, she slept up there (fs14).

Participants indicated that even when they did see their parents, their parents were emotionally absent. They perceived their parents to be worried and have their minds focused on things other than the well siblings. "I got to see my mum like a lot of the time, but she hardly spoke to us sometimes because she was too busy..." (fs13). Siblings were seldom given the opportunity to talk to their parents about their thoughts and feelings "because everyone was so busy and like, 'Excuse me, remember me, the other child?' ...But yeah, everyone was like busy and sort of wrapped up about what happened" (fs16). The long-term impact of decreased parental time and attention on siblings was profound and on-going, as indicated by the adult siblings.

For years and years and years and years I can remember every weekend dad would be gone [with my brother]....I guess I was a little bit lonely ... mum and dad were always with him ... I wouldn't say it was bad, I just learnt to deal with it... (ms26).

Differential Treatment

The *differential treatment* siblings received in relation to their injured brother or sister, further threatened their place and safety in the family unit. "When he first came home, she (mother) was looking after him most of the time" (fs13). Siblings noticed that their parents' time, energy and resources continued to be

disproportionately allocated to their injured sibling and that this was relentless given their on-going disability.

It kind of I suppose, puts a bit of strain because mum or whatever has to look after Ross and like we don't have to suffer or anything but in that instance, Ross comes first kind of thing because he is sick, so yeah. And, because he is sick like so often I think I kind of get, not sick of it, but like just think you know, because he's always like got a headache or whatever... (fs14).

Some siblings noticed that their injured brother or sister was spoilt and received material goods more often and more easily than themselves.

Jerry gets spoilt rotten. Even though he is the oldest, [but] there are still other kids ... that live here. He gets spoilt and ... he gets ... money, usually, just whatever he wants. Whatever he says goes, sort of thing, which can really annoy you because if he gets everything then there is nothing for anyone else... (fs14).

However, it was not only the imbalance of material possessions that upset siblings, but also the perceived effort and time the parents put into the child with an ABI. For example, an eighteen-year-old said of his sibling with an ABI,

From dad she gets everything, if she wants something she gets it, she gets all sorts of junk. Dad goes shopping and he'll bring her home a present, it just makes me sick....Like he has given me tons too but he just gives me cash which I have no problems with, but he gets her little presents and things (ms18).

Siblings also indicated that parents were more likely to overlook the injured child's wrongful behavior. Parents appeared to make more concessions for the injured child than they did for siblings, which fuelled the perception of differential treatment. "I am angry at him, but not that angry. Because sometimes when I want to like be with mum, he is always first because he has had his injury" (fs10). Similarly, another sibling noted,

Well dad, like before the accident, was always yelling at her because she was always rude to him, because she was thirteen, and so he got angry at her all the

time, and then after the accident he was like never yelling at her, he is like, when she does something wrong it's like 'Oh well'. Then they will go and yell at me and blame it on me....Mum yells at her a lot but she doesn't yell at her as much as me (fs13).

Despite the recognition that parents could not always control the injured child, siblings indicated that they still felt a lack of support from their parents, especially when in conflict with their injured sibling. As described by one fourteen-year-old who said she became "peevish I suppose because like ... he knows you are [right] and I know [I'm right but], it is hard because like ... mum can't [say anything]. Even though she probably knows he's wrong, she still has to like [say nothing]" (fs14). Likewise, another sibling explained, "...they (parents) would take her side, like say to me 'just forgive her'" (ms18). Such incidents enhanced siblings' sense of inequity, insecurity and isolation and exacerbated their perception that they were not as important to their parents as their injured sibling. At times, siblings reported feeling resentful towards their parents.

I just used to get angry, especially at my parents....And when she is say being rude to my friends and all that ... I'd punch the odd hole in the wall and just be angry and that -- at them [parents] mainly (ms18).

The adult siblings highlighted the permanence of the changes resulting from an ABI, describing the losses of parental attention and the concessions parents made for their injured brother or sister as an ongoing process that they were required to accept in their lives.

Differential treatment happened repeatedly through that time and also now ... I get a bit sick of it sometimes still. I still think why is [he capable of doing] anything and then he still needs to be looked after and I can't? I just get a little bit irritated sometimes (fs35).

The degree of exposure to this situation, however, determined its level of impact.

Typically, adult siblings who lived away from the family home were less exposed to the conditions of differential treatment than siblings who still lived at home.

Loss of Belonging

Siblings felt isolated and rejected by the family system. Their sense of belonging and their place in the family was threatened. They perceived their injured sibling to be closer to parents. “Oh we are close, but not as close as Costa [injured siblings] and them [parents]” (ms13). Seven years after his brother sustained an ABI, one twelve-year-old sibling said, “my parents, they are spending a lot more time with him, because he’s got a disability...” (ms12). When asked if he could describe any times when he spent special moments with his parents alone, he replied “no not really” (ms12).

As a result of spending less time with their parents, siblings felt lonely and “sad ... I missed her (mum) ... while [my brother] was in hospital and a little bit after” (fs13). Siblings described feeling loneliness for years after the injury.

I never used to get to spend much time with my parents it was really hard....So, it was just mainly the first one or two years [that I was lonely] because I never used to see mum and dad much, feeling lonely. It’s alright now, I see them a lot (ms14).

The general lack of acknowledgement and support for what they were experiencing further fuelled siblings’ sense of isolation.

I remember feeling left out when people would ring me for information, like relatives and friends ... and they would go ‘how’s your mom, how’s your brother (with an ABI)?’ ...And I was like what about Fred (other well sibling) and I?...Not mum and dad so much ... but feeling left out that other people didn’t consider us (fs20).

Feeling displaced in the family system, isolated from parents and other support, as well as accompanying loneliness, had potential for long lasting consequences.

Another adult sibling said that the isolation she felt as a result of the loss of her parents' emotional and physical availability was particularly difficult for her as an adolescent going through a difficult stage.

I remember distinctly one day ... I had to catch the bus into town. And ... my brother was at the hospital still ... I can even remember what dress I was wearing ... I remember hopping on the bus and having left home - no-one was there 'cause they were all at the hospital....The bus used to drive past the hospital and I was sitting on that bus crying the whole way to town. And I had no idea what about, but it was like this feeling of, you know, I'm here, I'm home on my own, I'm getting on the bus I'm going to work, nobody cares what I'm doing, you know, I just passed my first typing test, but nobody cares. It's -- they're all busy. And there they all are at the hospital that we're just passing, you know?...Another time I remember was when my brother became conscious again. He had no memory of me visiting and I wasn't there when he became conscious....And, I remember mum made some vague statement about -- 'he has no memory of you visiting, but I told him you came'. And I thought 'couldn't she have made more fuss about that, couldn't you have said, yes, she was here every day?' You know? So, that was another time where I felt, you know, you don't really belong any more. It's like, um, it's -- that's the family and you're here and nobody's going to make a fuss that you weren't there....And that came at a time too, when I felt, like most teenagers do, that you've grown up and you don't need them anyway. So it's sort of -- it's a -- it's a, a mix of things happening (fs35).

Family Turmoil

In addition to the loss of parental time and attention, siblings noticed that the patterns and dynamics in their family changed, becoming unpredictable and erratic. The turmoil in the family unit included conflict between family members, change to the family routine, and heightened stress as family members tried to negotiate the changes caused by an ABI. "Everyone sort of changed and like everyone's moods

changed ... arguments and fights and things ... they stress me out really bad” (fs14).

The turmoil was often centered on the changed behavior of the injured sibling.

He just gets like kind of uncontrollable kind of sometimes. Like yeah and he like swears or whatever at mum and he gets like in a rage kind of thing....Kind of a little bit stressful, I stress, I just think ‘Oh my God!’ (fs14).

[In the beginning] it turned into fights because I was always fighting with her [injured sibling] a lot and you know, mum and dad would then fight because mum would be sticking up for me and then the other way around dad would be trying to please everyone and so it turned into a few fights and ... just fighting between ourselves which shouldn’t have been, but it happens... (ms18).

The continually changing nature of an ABI ensured that these patterns of turmoil persisted indefinitely or re-emerged repeatedly.

The strain and stress siblings observed between their parents added to their perception that the family was vulnerable. Siblings were aware that the origin of parental tension was the conditions created by an ABI. For some siblings, it was the first time their parental system was perceived to be vulnerable to breakdown. The astute awareness most siblings had of the situation is highlighted in the following quote.

[My parents] changed in relationship type thing because they were fighting a lot ... like, they were so stressed out about Margaret [injured sibling] that when they got to sorting out the pay that dad got, or something like that, ... they were like ‘Oh, we don’t have enough money to do this, why don’t you stop buying beer’ and dad would go ‘I like beer’ and mum would go ‘Stop buying it’ and stuff like that... (ms14).

In addition to the vulnerability of the parental system, the *upheaval of routine* and the interruption of their life plans, contributed to siblings’ sense of vulnerability and unpredictability while their injured sibling was in hospital and for some time after.

We drove up every night, like practically every night and my dad would like drive up every morning and then come back down and pick us up and drive back up, and then drive down and then drive back down in the morning (fs14).

Younger siblings were particularly disrupted, as they were more reliant than older siblings on their parents. Many siblings recalled “I couldn’t go out with my friends and that on weekends, I would go up to the hospital instead” (fs13), or “I didn’t have [my friends] over ... mum and dad were always at the hospital” (ms10). Similarly, other siblings said “...I used to play soccer when I was young and that stopped for a couple of years because of his [ABI]” (ms13) and another, “we did athletics and that stopped” (fs14). Some siblings even missed school for many weeks while their siblings were in hospital. Not surprisingly, this loss of time and attention and the upheaval of routine impacted on the daily lives of siblings. “With my dad staying there [at the hospital] I didn’t do as well [with my sport]” (fs13). Siblings also often missed out on planned family activities. Due to the unpredictable nature of the ABI, family events were often cancelled. “It’s really hard actually because we stay home and stuff like that” (ms12). “If it’s like a family thing and James can’t go ‘cause he is in a wheelchair, then the whole family can’t go” (fs10). It seemed that nothing in the siblings’ lives was left uninterrupted, even planned activities became vulnerable to change.

The change in the family routine, particularly in the initial stages of the child’s recovery, also isolated siblings from their friendship circles and routine including, school, and sport. *Over-protective parents* added to this isolation by restricting siblings from engaging in activities of all kinds and highlighting their sense of being different from their peers.

I really have to have them [friends] come over here because like if I wanted to sleep or something like that, if they wanted me to sleep over there, I am not allowed to because my mum and my dad get too worried or something like that. So they have to come over here more (ms12).

I think because something happened to Bob, that makes mum and dad really over protective ... I think like they don't want anything else to you know happen so I don't know....It annoys me sometimes like if I want to go out somewhere [and they won't let me]....I understand why because like what has happened to Bob... (fs14).

Parental Vulnerability

Parents, who prior to the ABI were the siblings' pillars of support, were no longer available to protect or comfort them. Siblings observed that their parents "were always upset," which made them feel "bad" (ms13). Observing their *parents' sorrow* was also frightening for siblings and exacerbated their isolation and sense of vulnerability. One sibling said his father, who usually knew the answers to everything, no longer provided the same sense of certainty.

I felt sorry for dad 'cause I knew he didn't show he was much upset, but I knew he would have been. He had to quit work for a year and that to stay with her and that. Yeah, I felt sorry for dad and mum really....(and) mum didn't go up for the first week - she was too worried (ms18).

Not surprisingly, seeing their parents upset resulted in the siblings themselves becoming distressed and upset, exacerbating their sense of vulnerability. One participant who was ten years old at the time of his brother's injury said,

It affected the relationship between me and my parents ... oh not really with my dad, but my mum because she was always upset. And, whenever my mum gets upset, I usually get upset, for some reason I don't know why....And then she [mum] would start crying and I would say 'then why are you crying?' And then five minutes later I'd be like 'Mum!!!' [imitates crying] (ms14).

Most siblings, as described by a male participant who was fifteen years old when his brother sustained an ABI, shared this feeling. "...the worst part [was] looking at my parents when all that was going on. You know, I'd see them and I'd get upset....Like, seeing my parents -- that was the worst thing, like just seeing how they

were” (ms17). Even after a few years post-injury, participants were aware of the burden and stress their parents had experienced “Poor dad, he has copped a lot from the years...” (ms14).

Similarly, parents who were *overly protective* fuelled siblings’ perception that their parents lacked control over the unpredictable and vulnerable life conditions. As noted by Bruce and Schultz (2001), “parents have the potential to amplify or de-emphasize the dangers of the world” (p. 98). In the current study, such parental messages added to the siblings’ sense of unpredictability, vulnerability and loss of control. Displaying their emotions and/or being overly protective not only continued the perception that the child with an ABI was vulnerable, it also sent messages to the siblings that the world was not safe.

Siblings’ perceptions of their parents changed as a result of seeing them in this state of vulnerability. They recognized that their parents were struggling to cope, did not always have the answers, and could not always provide comfort. The day her brother was injured one sibling who was seventeen at the time said,

As soon as I saw my dad and he just got out of the car and burst into tears, that is one thing that will always stay in my mind. You don’t see your father cry very often ... and [I realized then], ‘oh my God, this is really bad’ ... and I went to total panic then and that awful stomach feeling that you get (fs20).

In response to their parents’ sorrow, siblings exhibited sympathy and compassion, but also felt even more helpless, frightened and isolated because the people they previously turned to for comfort, their parents, were no longer able to support them.

It was really hard to sort of anchor yourself to them [parents]. You always think that your parents are so in control and here they are in a situation where they feel they are so helpless, and you are helpless as well but you always look to them for a bit of guidance. And, I think that was a big learning thing then to

realize we are all our own persons and no one is more strong or more in control than anyone else....Just to see them so awfully upset was upsetting, apart from the whole thing that had happened, just to realize that they were having a hard time as well....People think parents can solve the problems of the world [but] they had no control, they were just as worried as I was (fs20).

Loss of Emotional Equilibrium: Emotional Turmoil

The conditions that resulted in a loss of environmental equilibrium by highlighting vulnerability and unpredictability also resulted in a loss of emotional equilibrium. The sudden deviation between the siblings' world as they knew it and the world that resulted from the conditions described above (i.e., vulnerability of life; vulnerability of the family unit) caused siblings to experience emotional turmoil.

You just feel so devastated, you know. You feel so in turmoil, inside. You don't know what to feel. 'Cause you don't really know what's happened....You don't know what to feel sad about, but everyone's feeling so sad, and stressed, so, you think you have to too. So it's like it's real turmoil inside... (fs35).

Siblings experienced a complex mix of emotions in reaction to the loss of equilibrium in their worlds. They reported acute episodes of anxiety amidst chronic worry. In addition they experienced ambivalent emotions, often oscillating rapidly between feelings of aggravation and compassion. Further complicating these emotions was a relentless sense of disenfranchised loss and grief underlying the siblings' experience. The enduring nature of the conditions presented above continually fed and reinforced this loss of emotional equilibrium.

Acute Anxiety and Chronic Worry

Siblings experienced acute anxiety in reaction to the sudden onset of an ABI, which manifested as chronic worry over time. Episodes of anxiety, however, were triggered by internal or external stimuli that, once again, confronted siblings with the possible mortality of their brother or sister.

Siblings experienced intense anxiety as they grappled with the possible death of their injured sibling. “First week when she was in intensive care I was upset heaps. I couldn’t even sleep or nothing, I was that worried” (ms18). “I was so worried about Rick and I was worried about mum and dad” (fs20). “I felt numb and I would cry myself to sleep many nights...” (fs16). Siblings experienced shock, bewilderment, and acute anxiety as they were confronted suddenly with the tumultuous conditions that turned their lives upside down.

Yeah everyone’s emotions were going a bit whacked, sort of like shock, like hitting a brick wall. I was like, I don’t know, I can’t think of it....It was just like you know, stop please! (fs16).

Siblings searched for reasons to explain the random insult of an ABI. Many asked “why us?” “Why it was Costa and not anybody else?”(ms13). Exacerbating siblings’ confusion, and thus anxiety, was a *lack of understanding and information* about ABI and the surrounding circumstances. Parents often attempted to shelter siblings from information or exposure to ICU, however, hospital staff observed that excluding siblings led them to imagine a situation worse than reality. This was confirmed by siblings as illustrated by an eleven-year-old boy whose brother was in a stable condition. “I wasn’t allowed to see him because I don’t know why? ... I peeked

in, he had a big bandage around his head and all these wires connected to him ... [I thought] he was going to die” (ms14).

Once their injured sibling was out of acute danger, siblings still perceived their world as vulnerable to fate and to circumstances, as illustrated above. “When you see your brother so close to death, it makes it very real the possibility that you could see them there again” (fs20). As a result, the intense anxiety siblings experienced initially, became *chronic worry* for their injured sibling’s safety, regardless of where they were or what they were doing.

I was always thinking of her ... even now when she is driving and that ... I’m always thinking, hope she is all right. I think about her heaps though at work and that sometimes....And then I would worry if she was out (ms18).

Consistent with the ongoing nature of an ABI, siblings worried about the future health outcomes of their injured brother or sister, even after several years, “...Is he going to get bad or is he going to get well?” (ms14), or “I worry about if he is ever going to get off all the tablets he takes....If he is ever going to get better or not?” (ms12). They also worried for their brother or sister’s future. “Like her school work, like before the accident she was the smartest person in the grade, and now she is like only getting C’s and stuff. I sort of worry about it there...” (fs13).

Siblings’ worry was also associated with observed behavior in their injured brother or sister that they did not recognize or understand, fearing that it may be the result of something more serious, even if the behavior was “normal”, like sleep talking.

I sometimes feel worried. Sometimes she talks during her sleep and I have no idea why she talks ... I have noticed it happening this year and last year, but I don’t know. I would know if she had always done that ... I worry about that, I don’t know what’s going to happen, she starts talking like she’s talking to herself like this ... I don’t know what’s happening....(And) I worry about her safety... (ms11).

This type of worry usually resulted from having very little or mixed understanding about the long-term prognosis and consequences of an ABI. When their sibling became ill from a headache, or other common ailments, some siblings worried that this was a symptom or relapse of the ABI, and were worried about what it might mean. “I just worry about her heaps when she says she’s got headaches and that. I think, ‘God, I hope [it’s not] something after the accident [that] caused that’” (ms18). One thirteen-year-old said that when her brother became sick she worried about him “because, just in case it was a stroke or something....Not exactly the same thing but like sick like that again” (fs13).

Due to the enduring and *unpredictable* nature of ABI, however, siblings’ chronic worry periodically escalated to acute anxiety, regardless of the recovery status of their injured sibling. Acute anxiety was *triggered* by external or internal stimuli associated with the onset of the event, or activity, which siblings perceived as a potential threat to their injured sibling's life. “Every time you hear the phone ring at night you are like ‘Oh my God, what has happened?’” (fs20). “Hear a siren or something and I think ‘God, I hope it’s not her’ ... [sigh]” (ms18). Siblings’ anxiety was even triggered when their injured sibling was involved in everyday activities that presented minimal risk for re-injury. “He’ll jump on my roller-blades or something, and that’s all it takes to hit his head again, and he could even die” (ms17).

In addition, siblings’ anxiety was triggered by conversation about ABI, *overly protective parents*, anniversaries of the event, and internal stimuli such as nightmares and flashbacks about the event.

Ambivalent Emotions

In response to the loss of environmental equilibrium caused by the changes in the injured child, sibling sub-system and family unit, siblings also experienced a multifaceted range of intense and conflicting emotions. Siblings experienced *frustration, annoyance, jealousy* and *embarrassment*, in response to these changes. Dialectically, siblings also experienced immense *sorrow* and *empathy* for their injured brother or sister's losses, which led them to feel *guilt*.

For instance, as a result of the enormous changes and the perceived unpredictability of their injured brother or sister, siblings described feeling acute *stress* and *frustration*, "it is very stressful sometimes ... you can just sort of like go and scream" (ms13); as well as *annoyance*, "like, now she can get annoying to me, but before the accident she wouldn't have" (ms18). One ten-year-old said, "...he always bugs me....I am always angry at him because he is always slow ... he's always walking up the stairs slow and I always want to go faster because I have a phone call or something and he always talks slow" (fs10).

Most siblings also reported that their injured brother or sister was no longer able to gauge social situations and was uninhibited in their behavior. This inappropriate social behavior impacted significantly on the siblings, "I mean ... he gets himself into a bit of trouble, like you know we nearly got into a big blue [fight] with a gang because of the brain injury, they call it no inhibitions, is that what it is?" (ms17). This behavior also impacted on siblings' interactions with their friends. "[I'd] Rather my friends come here [to play], but he [brother with ABI] goes ape" (ms14). Thus, one of the most common emotions resulting from such interactions was *embarrassment*.

He acts a bit [inappropriately] in public ... it's a bit embarrassing. I just think ... what are you doing and walk away ... so people can't see me. I get embarrassed, not all the time, I mean he is getting a lot better as time goes on... (ms17).

Embarrassing and inappropriate behavior further threatened siblings' loss of security because it had potential to threaten their safety and belonging in their own friendship circles. This was particularly important to adolescent siblings, as their image was of utmost importance. One fourteen-year-old said of his friends,

Oh, I don't even think I've brought them home actually. I don't know why? Maybe I just thought, 'I guess I better go to your house,' because I don't think their parents would have let them come to me with a disabled person around the house ... I'm not sure why, maybe I'm wrong....It's like oh, maybe they might feel a bit awkward ... so, ah, 'Can I stay at your house?' (ms14).

Others said they felt they had to make excuses for their injured sibling's behavior.

I always warn people before they ring – 'if my sister answers the phone and she's rude, sorry, you are just going to have to accept it because that is what it is like...' Like I've got to apologize after [her] in shops and that – say 'sorry for that, you know she had an accident and that.' I just feel embarrassed (ms18).

In addition to feeling annoyance and embarrassment, many siblings also felt jealousy. Even older siblings who understood the loss of attention from parents said they felt jealous and left out.

Annoyance, stupid little bitch, she always has to take all the attention....Like I sort of got jealous, everyone's [attention] on her. It was like 'excuse me, I am here, with the family'I don't know, I am going to have to put up with the lot of it... (fs16).

It sort of got me jealous a bit when she (mother) was never at home for us, and like, I was the only one. I had to do all my assignments without her even reading over them or whatever, or doing everything myself, but I got there eventually (fs14).

Not surprisingly, siblings said that the loss of time spent with their parents not only resulted in them feeling *jealous*, but that it also isolated them from the family system.

When she first came out of hospital ... I was a bit jealous....They [parents] were not paying attention, it just felt different. It was, 'Betty [sibling with ABI] this' and 'Betty that', but it should have been. But when I was only fifteen ... it was a bit hard to understand (ms18).

In contrast to these intense feelings of annoyance, embarrassment and jealousy, siblings felt a great sense of *sorrow* and *empathy* for their brother or sister with an ABI. This sorrow added to the siblings' emotional turmoil but represented a long-term and deeper theme that underpinned the siblings' emotions. Siblings were deeply affected by the experience of their sibling's near-death, and the physical, cognitive, and behavioral changes they had endured as a result. Siblings were also saddened by their injured brother or sister's apparent loneliness, loss of friends, and difficulties at school. "Sometimes when I see her and she is like by herself, I kind of feel sorry for her....Like sometimes at school she is by herself" (fs13), or, "I wish that ... people wouldn't be as cruel to him" (fs12). Another sibling said that it was his "...wish that Tim ... could be a bit happier at school because he hates school at the moment" (ms13).

Siblings expressed a deep sense of sorrow for the losses and limitations that their injured sibling's experienced.

I feel sorry for her sometimes when she goes off on her trial job -- she doesn't get paid for it -- but she goes three times a week....And, I feel sorry for her doing that because she used to love her job....But, I feel sorry for her, God (ms18).

They also described a strong empathy for their injured sibling. When asked what the hardest times were since the ABI onset, one sibling said,

It's seeing him not do what he could do before, he was one of the best soccer players in [home town]. He made the [state] team, I mean he could have gone all the way, I mean he wants to go and smash the driver because he can't go and play soccer. The hardest time is seeing him not do what he could, and that's when he gets depressed, like he used to be able to work and he was doing lots of sport. Now he has only got a couple of shifts a fortnight, I get depressed as well like seeing him depressed gets me depressed....I just want to see him get back and do what he wants to do (ms17).

The extent of their brother or sister's limitations and what they were missing as a result of their condition did not escape siblings' attention.

Well Costa can't really like go out. After the [ABI] he used to be in [Scouts] and no one can really understand what he says anymore, which makes him sad ... I just feel sorry for him....Sometimes, I know why he doesn't really want to do it [therapy], because he's, it would just be so boring for him, because he does it three days a week in hospital for about four hours a day....Sometimes at nights Costa gets really sad about what happens and he has to do more exercises and stuff which is just more onto what has happened to him (ms13).

One younger sibling expressed the emotional ambivalence most siblings felt.

She was confused about her feelings towards her brother after his ABI, "its just so all jumbled up you know, I don't know ... I don't know whether I should feel sorry for him..." (fs12).

As a consequence of the interplay between the feelings of annoyance, embarrassment, and/or jealousy, and their sorrow for their injured brother or sister, siblings also experienced *guilt*. Some siblings felt immense guilt that it was their brother or sister who was injured and not them. "I was really mad that it happened to him and not me ... [I felt] guilt that it wasn't me" (fs20). Thus, they did not feel justified in becoming angry, annoyed, jealous or embarrassed because they knew that the changes in their sibling were the result of the injury, and thus they felt guilty for having these feelings.

The siblings' guilt about their annoyance, embarrassment and jealousy was further fuelled by the vivid memory of their brother or sisters' vulnerable health situation in which they nearly died. Siblings felt unjust in complaining because the life of their brother or sister was spared.

She is alright now. I don't care what ... how embarrassed I was at the time, it was funny after it. And, I would rather her be embarrassing me than not being there at all. That is basically it....That is probably the best thing, yeah. I wouldn't have cared if she was in a wheelchair or nothing, I would've wheeled her around, but just so long as she is alright (ms18).

Siblings also indicated that they felt a sense of guilt about their ability to maintain their goals and continue their lives relatively unaffected.

It's like, 'why am I still the same person?' You know? That's what he says. I say 'yeah I know, I know'....You see he sort of gets it because like I am doing all what I want to do and I am playing sport and he really wants to get back into soccer [but he can't] (ms17).

Siblings commonly highlighted their own abilities when speaking about their injured brother or sisters' inabilities. Implicit in these quotes is an underlying sense of guilt felt by the participants for the fact they were continuing life and pursuing goals that their brother or sisters were no longer able to achieve.

...he doesn't have very many friends, ... he doesn't go out much and like I am sort of always at Beck's [place] or like movies or whatever. So it is like it is kind of not very fair because like he doesn't really [go out or have friends], and I am always going out and it's kind of not very [fair]... (fs14).

One sibling even expressed feeling guilt for wanting to have fun doing things that were a part of her family life prior to her brother's ABI.

[I felt] so guilty. Every time I did something or started enjoying myself I would start thinking I can't do this, I can't have fun. I would just feel guilty about everything -- and then later wanting to do things like go camping and asking to go and then feeling guilty because we couldn't go, or because I had even bothered asking....[I] still feel like Rick never got to do [this and that] and mum and dad are at home working so hard looking after him and I am here (fs20).

Disenfranchised Loss and Grief

One consequence of this tumultuous mix of emotions was the sense that grief should not be expressed. Most siblings experienced a severe sense of loss and grief that they were unable to discuss. They were grieving the “loss” of a sibling who was still alive. “Every day of my life it feels like I have lost a part of him forever” (ms17). Siblings grieved the loss of the child that was, “I know he will never be the same again” (ms13), and wished for the world that should have been.

Every now and then you just feel sad about it ... think about what could have been....It's hard because he has only got the mental capacity of a four and a half year old, so it's like a relationship with a big four and a half year old (ms26).

Siblings described feeling loss in all areas of their lives. “If I am ever around and I am doing something fun, just around here, I think I wish Costa was here and he could do this” (ms13). Another sibling said,

I think of how much he has changed ... I would much rather the old Blair back but you can't [have him back]. You know, you just think and you get the shits and you just want it to be the way it was... (ms17).

The non-finite nature of the losses from an ABI, however, meant that siblings experienced a continual grieving process that was often not acknowledged or validated. The grieving process was heightened by the potency of the siblings' schemas about their assumptive world, or the world that should have been.

Everyone is grieving for their own little part of Rick [Sure] Rick is still alive with us, [but] it is the hardest thing with head injury because you are grieving for someone who is still alive. And it is not as well accepted by society I think, because I had a friend who died two months after Rick's accident and that was horrible because I was still getting over Rick's accident and then this girl died....People were saying 'at least you've got Rick, Rick's still here, there's

still hope'. And I was still thinking there is so much more closure you [need] ... people would be going, there's so much hope, [but with brain injury] ... your own family grieve for each loss. The thing is there is sort of like a constant grieving now for each stage, you know when Rick turned eighteen, when he was meant to finish school....We went to the valedictory service there with him and saw all his friends there, and like I still get upset when I see his mates at college ... seeing those things is a constant reminder [of the loss]....Knowing he now may never be able to have a family, I will never be an aunty to one of his kids, you know all those sort of things that you keep all the way through....Or not being able to go out drinking with him....It still makes me sad if I go and I see all these boys going out and doing exactly what he would be doing....At each life stage we are going to be grieving for Rick's loss (fs21).

On the other hand, the *appreciation of life* that siblings felt for their brother or sister's life prevented them from acknowledging their loss and grief as legitimate. They perceived that they had no right to grieve since the life of their sibling had been spared. When this appreciation of life is superimposed on the loss experienced by siblings, the result is what Doka (1989) termed *disenfranchised grief*. Siblings did not feel the right to grieve for what was lost, but rather a need to be grateful. "The fact that she's still alive is important" (fs16). "What has happened to Bob has made me like love him more than I did....Like [I] see how more important he is now ... because ... I thought he was going to die, when he was in [ICU], I got really sad" (ms13). Siblings were now aware of the vulnerability of life and their daily experiences were filtered through this lens. They felt grateful for the life of their injured sibling and did not want to tempt fate by being ungrateful.

It just makes you realize what you've still got, I mean you don't know how much you miss something until it is gone....I am still the same. Exactly the same, it's just that I like my brother, you know, I love him but you only say that when you are about to die or something, 'I love you Blair'. But, I'd never say it to him you know, out the back having a cigarette or something....Like we still cared about each other but we never showed it [before the injury]....You could die anytime, so it's a good relationship [since the injury] (ms17).

In addition, guilt arising from the interplay of ambivalent emotions prevented siblings from acknowledging the legitimacy of their own losses and associated feelings (e.g., loss of parental attention, jealousy, annoyance, etc.) following an ABI. Siblings perceived themselves to be the *lucky ones*, which was implicitly reinforced by the lack of attention and acknowledgement they received from parents, friends and their communities. Thus, siblings' own losses were disenfranchised, perpetuating their ambivalent emotions.

With my brother, our relationship is pretty cool ... It annoys me though because I will get angry and then I'll be sitting there going 'I shouldn't have said that' and then I think 'I'm not going to apologize, but then [I do]. It's really hard to hold a grudge with him....I've got to remember ... the only reason people surrounding him care [so much for him] and the reasons I get jealous, is because of how he is and then I think, well, I would rather be the way I am and have these situations (loss of attention) than be the way he is with his. Because his life is a hell of a lot harder than mine, I just remember that I've got it pretty good, you know, I have my hearing, my sight and all (cfs15).

Summary

In summary, the BPS problem that arose for siblings following their brother or sisters' ABI was a loss of environmental and emotional equilibrium. Gone were aspects of siblings' identity, predictability and safety. Siblings found themselves "lost between worlds" (Bruce & Schultz, 2001, p. 5), the *world that should be* and the world that became filled with uncertainty and vulnerability. The loss of environmental equilibrium threatened the safety and stability of the siblings' lives. Suddenly, siblings were exposed to a series of traumatic, destabilizing, and unfamiliar events that changed their perception of themselves, their family, and their brother or sister with an ABI. Importantly, these changes seemed to last into adulthood, requiring siblings to integrate these losses and their associated meaning into their lives.

As a result of an ABI, siblings were exposed to *unforeseen circumstances* and *mortality*, which challenged their sense of predictability and security. The brother or sister and the relationship siblings had known prior to the ABI also suddenly lacked familiarity. Even after a long period of time, siblings perceived their brother or sister to be vulnerable to re-injury or death, therefore prolonging their sense of uncertainty.

Siblings were also confronted with the *vulnerability of their family system*. *Absent parents, differential treatment, family turmoil, and parental vulnerability* were conditions that undermined the siblings' sense of security, safety, predictability, comfort, and control in their family system. The dynamics and patterns within their families changed and challenged existing patterns in the sibling sub-system. For most siblings the previously established sibling sub-system was based on competition and rivalry for parents' attention (Bank & Kahn, 1997). The impact of an ABI necessitated extra attention for the injured sibling, decreasing competition between siblings, and changing patterns of familiarity. The comfort and security in the *world that was* no longer existed and these conditions resulted in a turning point for the siblings who became aware of their own vulnerability.

Not surprisingly, the sources of environmental disequilibrium resulted in a loss of emotional equilibrium for siblings. Siblings experienced emotional turmoil in that they oscillated between feeling acute anxiety, chronic worry, ambivalent emotions and disenfranchised loss and grief. The on-going sequelae of an ABI indicated that reaching a resolution about the losses from an ABI was difficult for siblings. Emotions that prior to the ABI were considered "normal" (e.g. jealousy and annoyance in the sibling relationship) were suddenly questioned, leading to guilt and further emotional turmoil. Thus, ABI resulted in many primary and secondary losses for siblings.

Siblings not only “lost” the familiarity of their brother or sister, they also lost the comfort of previous family rules and patterns, and the carelessness of the emotions they felt.

The Evolution of Losing Equilibrium

The BPS problem, *losing equilibrium*, illustrated through the categories *vulnerability of the assumptive world* and *emotional turmoil* illustrated that, following ABI onset, siblings experienced a great loss of environmental and emotional equilibrium. Losing equilibrium transcended a variety of factors such as age, gender, time since injury, injury severity and injury type. Instead, the level of exposure to the conditions above and the degree of discrepancy it presented from the *world that should be* influenced the loss of equilibrium experienced by siblings.

According to Bruce and Schultz (2001), through the process of socialization, the familiar becomes “the world that should be” and translates into a reality that is taken for granted. Over time, familiarity within the world emerges and reality is composed of a succession of transactions with the environment. This reality becomes the baseline from which a sense of loss is interpreted. The data suggested that following the onset of an ABI, the discrepancy between the siblings’ “world that was” and their world following an ABI is initially high, particularly for siblings with a high degree of exposure to the conditions (e.g., the unforeseen, mortality).

Siblings described that the losses became “easier with time” (ms16) and that “the further away from the accident time gets, the more “normal” [the new situation] becomes” (ms18). However, the data presented above also illustrated that the enduring nature of an ABI continually threatened the equilibrium of the siblings’ worlds.

Siblings described a range of conditions by which they were impacted for many years post injury, as well as situations that presented new losses over time. Thus, equilibrium fluctuated in degree over time, constantly threatened and triggered by the ongoing conditions arising from a child's ABI and its associated losses. This concept is illustrated in Figure 5.1.

Thus, for siblings who had developed an established relationship with their brother or sister prior to an ABI, the loss of equilibrium was likely to be higher than for those who had always known their sibling to have an ABI, even though both experience similar challenges and conditions. Similarly, the more vulnerable the injured sibling was perceived to be, the more loss of equilibrium is likely to result for the siblings and their families.

Siblings who had not developed a relationship with their brother or sister prior to their injury, such as those siblings who were infants when their brother or sister became injured, often echoed comments similar to those expressed by siblings of children with congenital disability, such as, "this is all I have ever known" (fs10). In this sense, an ABI and its associated conditions were integrated as part of the world that developed.

Figure 5.1. A diagrammatic model of the evolution of losing equilibrium

While children who grew up with their brother or sisters' ABI and consequent disability do not experience the same level of disequilibrium initially, however, the threat of vulnerability due to the nature of an ABI sequelae was still an ongoing threat to the equilibrium of the system.

I have not lived any other way, so I can't really be sure that it is different ... from my point of view and from what I have seen around my friends [is] that people have their days, but in my house people have their months or weeks or whatever...(cfs15).

The evolving loss of environmental and emotional equilibrium that siblings experienced motivated them to regain equilibrium in order to restore a sense of predictability, safety, security and control. The strategies that siblings employed to regain equilibrium are described in Chapter 6.

CHAPTER 6

RESULTS

Regaining Equilibrium

This chapter describes the basic psychosocial (BPS) process of regaining equilibrium, the aim of which is to restore the siblings' sense of emotional and environmental security, safety, predictability, and control that was continually threatened by the conditions of disequilibrium presented in the previous chapter. The degree to which siblings were motivated to restore equilibrium appeared to be dependent on how much they perceived it to be lost. Regaining equilibrium involved two main processes, *navigating* and *sacrificing*. Although distinct, these processes often occurred simultaneously, and shared the common aim of regaining a sense of security, safety, predictability and control.

The process of *navigating* was a boundary-testing exercise where siblings learned to navigate their way around their *new world*. This process was most prominent in the initial stages of the ABI recovery when past exposure to the consequences of ABI was low, understanding of ABI was limited, and patterns for interacting in the *world that was* were at the forefront. Given the perpetually changing and enduring consequences of ABI, as new challenges were confronted, *navigating* continued to be employed by siblings as a means of managing the evolving loss of equilibrium.

The process of *sacrificing* usually followed *navigating*, although some siblings employed *sacrificing* strategies from the onset of the ABI. *Sacrificing* was the most common process employed by siblings to minimize the conditions that caused environmental and familial disequilibrium and vulnerability. Sacrificing behaviors

commonly required an understanding of ABI and a sense of perceived control over the conditions that caused disequilibrium, which tended to be learned through the process of *navigating*. These processes are outlined below and include the conditions and contexts under which each operated. The consequences of these processes and how they were managed are also discussed. A model illustrating the entire process of regaining equilibrium is presented in Figure 6.1.

Navigating

For siblings in this study, ABI was a psychosocial transition (Parkes, 1988) that required them to make internal and external adjustments in their worlds often with no preparation or warning. Siblings were often forced to become conscious about how to operate in their new world and adapt to the changes that emerged in their family system as a result of their brother or sister's ABI. *Navigating* was a necessary process employed by siblings to explore the boundaries in their *new world*, allowing them to make external and internal adjustments for regaining environmental and emotional equilibrium. *Navigating* was an evolving process of trial and error that continued to be employed many years following ABI. As conditions relating to the ABI changed and evolved, this process and its strategies assisted siblings to continually integrate and manage the conditions created by ABI. Due to the trial and error nature of *navigating*, some of the strategies employed by siblings inadvertently contributed to the loss of emotional and environmental equilibrium. These strategies were usually discarded by the siblings. *Navigating* involved a variety of strategies, namely, *challenging new rules with old tools, withdrawal, trying and buying, merging the familiar and*

unfamiliar, and *integrating*. Although presented separately and sequentially for the purpose of clarity, in practice these strategies sometimes occurred in unison.

Challenging New Rules with Old Tools

Until siblings were actually exposed to the enduring nature of their brother or sister's condition, many expected everything to remain as it had been prior to ABI. Many siblings adopted familiar patterns of behavior in an attempt to restore equilibrium in their family unit. These set of strategies were best labelled *challenging new rules with old tools* and involved adhering to the "old" rules when trying to manage the new and changed conditions imposed upon them by ABI.

For example, to restore the relationships and patterns of interaction that were evident in the *world that was*, siblings treated their injured sibling with the same set of relationship rules used prior to their ABI. Siblings bantered, teased, fought and engaged in physical and verbal play, and competitive rivalry when interacting with their injured brother or sister. However, instead of eliciting a familiar response, navigating the new situation with old rules often resulted in conflict, thus increasing siblings' emotional and environmental disequilibrium. "At the start I ... was expecting her to be normal. Like I would stir her like I normally do, and she couldn't take it and that's when we used to start fighting" (ms18). Similarly, another sibling commented, "like we try to be sarcastic to her and she doesn't know that we are being sarcastic, and she just gets really angry at us....She used to be like really sarcastic, but now it's just annoying" (fs13).

At the extreme level, some siblings tried to actively restore equilibrium by *fighting the injustice*. These techniques were designed to restore siblings' recognition,

acknowledgement, equality and belonging in the family system, particularly regarding *differential treatment* and the loss of *parental attention*. For instance, siblings commonly employed *attention seeking* behaviors and/or deliberate acts of *rebellion* to regain parental attention. “My attitude during that period [was] if I could find a tattooed [boyfriend] to take home, that was just perfect ... I found the rules and broke them” (fs35). Although these strategies were designed to restore the previous patterns of equality in the family unit, they were usually ineffective and resulted in greater environmental (e.g., unpredictability and fragility of injured sibling) and emotional (e.g., isolation) disequilibrium in the family. *Challenging new rules with old tools* was the least effective strategy for regaining a sense of emotional and environmental equilibrium, but seemed to play an important part in testing the boundaries of the new situation. Although this strategy was typically discarded because it increased disequilibrium, it was occasionally re-employed when new situations or challenges arose.

Withdrawal

At the other extreme, another strategy that siblings employed to regain environmental and emotional equilibrium was to *withdraw* in order to seek reprieve. This strategy was most prominent in periods of change and upheaval and was employed when other strategies did not appear to be effective for regaining equilibrium, or when siblings perceived themselves to have little or no control over the conditions causing disequilibrium. *Withdrawal* ranged from brief episodes of *escape* to long periods of mental, emotional and or physical withdrawal from the family.

Withdrawal in the form of *escape* usually followed intense outbursts of conflict and involved the siblings retreating to a bedroom or going out with friends to restore harmony. “I go out heaps now, sometimes to get away from her if she’s annoying me. Like, I’d rather go out than fight with her...” (ms18).

Siblings who *withdrew* for longer periods of time usually did so to seek emotional equilibrium, such as security and belonging outside of the family unit, and did so by moving out of home, or discontinuing engagement in family rituals and activities. “I am not around the house that much, never see him that much, I am always out” (ms14). A parent revealed, “ever since Cameron’s injury, Nigel (sibling) doesn’t want anything to do with the family, he says that the extra attention Cameron gets is unfair ... he doesn’t understand and he doesn’t even try to[so] he moved out of home with friends”. Siblings’ feelings of isolation and displacement were intensified when they were excluded from important family activities, such as their brother or sister’s rehabilitation process, and information to assist them to understand ABI. Withdrawal was the most likely response to such displacement.

I’d try and put my two bobs worth in, but no, that wasn’t right. I was only young, but I still knew ... then I thought ‘oh well, stuff you’ ... I thought, ‘oh well, if you’re going to be like that, I’ll go back to my friends’ (ms18).

However, siblings were most likely to withdraw permanently when they were caught in the cycle of *challenging new rules with old tools* and/or felt isolated from the family system, perceiving it to be impenetrable and exclusively focused on the child with ABI.

I just felt as though I didn’t belong any more....The really negative thing was that it cemented a rift at a very difficult time for me [teenage years] and highlighted the differential treatment between us....[The accident] isolated me enough that I moved away....I don’t think I would have done that otherwise. I

think I would have hung in there, my [teenage rebellion] would have ended, and I would've got back on track somehow. But I moved away. And um, I don't think that was a healthy, useful thing to do, at that age, anyway. So it isolated me. And that's something that I didn't have before....I moved back to the family...[when] I was about twenty four (fs35).

Withdrawal was usually a transient and cyclical strategy, whereby siblings withdrew from the family and sibling sub-system when they perceived challenges arising from ABI to be beyond their control and re-entered it when they felt safe again. Withdrawal in the form of escape was usually an effective strategy for reducing environmental and emotional disequilibrium. "If I'm frustrated, I go out for a drive, cruise around and that calms me down and I think 'what was I worried about?'" (ms14). However, despite providing momentary reprieve, longer-term withdrawal from the family unit sustained siblings' sense of isolation and vulnerability.

Typically, siblings transcended the strategies of *challenging new rules with old tools* and *withdrawal* (from the family unit) because although they provided momentary reprieve, they ultimately sustained the cycle of environmental and/or emotional disequilibrium. Instead, siblings employed a variety of other strategies to navigate the evolution of disequilibrium, which assisted them to transcend this unproductive cycle.

Trying and Buying

Trying and buying was generally a more useful strategy that involved a *trial and error* approach of introducing new rules and strategies in interactions with their injured sibling and parents, continuing the use of strategies that worked in minimizing disequilibrium and discarded those that did not. "I sort of found my own ways to get

around it and handle it ... [for example], if you say something and he yells at you, [you think] ‘Oh I won’t try that again!’” (ms13). This process of trying and buying was necessary for enhancing siblings’ understanding of managing ABI. “If I had my time again, I wouldn’t have been so argumentative with her ... [but] you’ve got to experience it” (ms18).

These strategies were learned through *observation* and action in the home, as well as, through others in similar situations. “I think I just picked it up over time” (fs14). Some examples illustrate how siblings learned new strategies for operating in their world.

I just found out by myself just looking around, try something and see if it worked....The doctors didn’t say nothing about it....You have got to ... take it as it comes and deal with it, not try and just get all the information and then see what he is doing. You pick up on it pretty quick....Like if you live with him then ... a couple of days you know what’s going on (ms17).

I ... just learned myself, by looking and seeing other people ... and talking to other people at the hospital ... other families. That’s how I [learnt]. Not from no doctors or nothing (ms18).

Siblings also *modeled* and took instruction from their parents about how to restore equilibrium in their new environment. Rather than mediating conflict between siblings, as would have happened prior to the ABI, parents instructed siblings discretely about how to minimize the conditions that caused the conflict. This *parental input* reinforced the permanence of the changed conditions in the family unit and was a reminder to the siblings that *challenging new rules with old tools* was both futile and not supported by parents. “Dad explained most of it to me as best as he could, and he tried to simplify it for me because I was only young then” (ms18). This process involved an understanding between siblings and parents about how to manage the

injured child's behavior so that their fragility and unpredictability was minimized.

Such strategies usually involved siblings engaging in sacrificing behaviors, described below, and "putting up with" behavior that they would have challenged prior to ABI.

This phenomenon is illustrated in the following example.

Sometimes I will have an argument with her ... and dad ... like leaves her (injured sibling) out of it and he'll call us away or he will quietly say 'calm down a bit' He says, 'just think back before her accident, she wasn't like that...' And when she is gone he'll say, 'you shouldn't say that to her, you don't want to upset her ... 'cause you don't know what she can do, you just can't trust her a hundred percent yet ... [because] she gets depressed ... you don't want to put pressure on her, she's trying her hardest' (ms18).

Thus, in order to restore equilibrium in the family unit, siblings adopted behaviors that minimized family disequilibrium and discarded those that maximized it.

Merging the Familiar and Unfamiliar

Consciously comparing their "new" sibling to who they were prior to the injury was another strategy that helped siblings to navigate disequilibrium. By understanding the impact of the disability, this strategy assisted siblings to merge the old and familiar world with the new. For example, one sibling said,

I always relate back to what she was like before the accident to now ... If she does something now that annoyed me before the accident I'll [complain], but not if it's new behavior, like being rude, I just sort of have to ignore it, because I know that's the change in her (ms18).

Understanding this difference was easier for siblings if they had visual and obvious evidence of the impact of ABI (e.g., using a wheelchair). Similarly, siblings who had a high level of exposure to the vulnerability of their sibling in hospital were more likely to understand the change in their brother or sister. Those who were

included in hospital meetings, were given *information* on ABI or who were informed about ABI by their parents, were also more likely to be sensitive to the familiar and unfamiliar.

Some siblings navigated the enormity of the losses by *minimizing* the changes evident in their “new” sibling by positively reframing the changes. For example, one sibling said, “It’s not that bad, you cope with it, and it’s nothing compared to what could have happened” (ms17). Similarly, another sibling said of his sister, “she was one of the lucky ones” (ms18). By minimizing the changes siblings were better able to merge the familiar with the unfamiliar.

In addition, experience, time and maturity facilitated siblings’ ability to merge the familiar and unfamiliar. “When she came out [of hospital] and I got a bit older that’s when I started to understand how she has changed and what brain damage was” (ms18). Understanding ABI helped siblings to better navigate disequilibrium, which in turn assisted them to employ strategies to combat their sense of emotional and environmental disequilibrium. Siblings learned to control the conditions that jeopardized the equilibrium.

Thus, as a result of *merging the familiar and the unfamiliar*, siblings grew to understand that the loss of equilibrium in their family unit (e.g., differential treatment) was determined by the conditions created by ABI rather than by the worth of the siblings. This *maturation* process was also evident in siblings who had only ever known their brother or sister with ABI, as illustrated in the following excerpt. Understanding the difference between the familiar and the unfamiliar and integrating the implications of ABI took maturity, time and insight, especially if the changes were subtle.

Sibling: When I was little I didn't really understand it, which was like, why is he getting more attention than me? But the hard bits were when I kind of felt a bit left out.

Interviewer: What made you realize that this is what he needs, he needs the extra attention – it's not because he is more special?

Sibling: Probably, it's kind of been, I have been told a lot, but you know when you are little you don't really listen to your parents, you are just like whatever. Probably around 12 or 13 (years) ... I think it probably would have been more the clicking of 13 because we had to move for [his] school....All my friends were going to one school and I was having to go to another one because of his needs. I kicked up a lot of dust about that because I really didn't approve of that and then I kind of figured it's not for him, it's for him, but it's not *for* him – it's for his needs and not for what he wants. So that was what made me realize (cfs15).

Integrating

Through the cumulative effect of the navigating processes (*challenging new rules with old tools, withdrawal, trying and buying, and merging the familiar with the unfamiliar*), siblings became resigned to the permanence of the ABI-related changes and integrated them into their new worlds. Many siblings commented on “just accepting it” (ms18). Like the nature of ABI, integrating ABI was an evolving process that happened through “learning new stuff” (ms18). Siblings said it was “bad at first but then you get used to it” (fs13). However, they indicated that the loss was still great and that they “still wouldn't mind if it would be the same sometimes” (ms18). Indeed, siblings indicated that although the changes were difficult, the evolving and unpredictable nature of ABI demanded them to continually integrate new changes into their lives. One sibling said, “You can't really stop it from happening because it does, so I don't know, you just have to live with it” (ms13). Other siblings shared this sentiment.

Because it happened we have got to deal with it....You can't really change that. That is who he is now, and accept it and work with it and not against it....I mean you have got to work with that and it doesn't matter what you think or how much you cry about it, it is not going to [change]....There's no point in saying 'if this or if that', it's happened so you have just got to get on with your life (ms17).

Navigating illustrates the strategies siblings used to integrate the evolving disequilibrium into their lives in order to regain a sense of equilibrium. Navigating generally resulted in the employment of sacrificing strategies, however, due to the evolving nature of ABI, siblings often moved between these two processes, particularly in times of change and when new rules were introduced.

Sacrificing

This section explicates one of the main strategies that siblings used to manage and restore equilibrium, namely *sacrificing*. *Sacrificing* was the most common strategy that siblings employed to restore equilibrium in their lives when they perceived it to be threatened or lost. *Sacrificing* involved a number of psychosocial and behavioral strategies whereby the siblings placed their own needs, goals, and desires second to that of their injured brother or sister in order to take responsibility for the prevention, or at least minimization, of environmental and emotional disequilibrium.

You stop your life completely to put it together to help Malcom ... you change your life completely to make him feel normal and better about himself....Totally change life and to this day we do things for Malcom to make him feel better (ms16).

Siblings sacrificed many aspects of themselves, their family position, their expression of emotion, and their childhood in an attempt to take responsibility for maintaining equilibrium in their vulnerable world. Siblings were motivated to self-

sacrifice to reduce the environmental and emotional discrepancy between the world that was and the current world. A primary condition associated with the process of sacrificing was the siblings' belief that their behavior had the ability to provide predictability and control.

Apart from the fact that you love your brother so much, you feel guilt that it was [them] and not [you], as well as seeing your parents upset....Apart from that, you just want things to be back to normal and you try to fix the situation to make things as normal as possible. You think if I do things correctly and hold back, then things will be more like normal, happy families again (fs20).

Siblings' exposure to the vulnerability of life was also a major influencing factor that underpinned their willingness to make sacrifices.

I got a big fright. I had never seen anyone so sick before. But it kind of made me realize, because I am horrible to him sometimes, but it kind of made me realize that you don't know when people are going to leave or whatever, so you have to be nice to them all the time (cfs15).

Sacrificing behaviors occurred from the onset of ABI and continued indefinitely, particularly when vulnerability, and thus disequilibrium, was perceived to be high. Although it was common for siblings to learn sacrificing behaviors through the process of *navigating* (e.g., trying and buying, parental input), some sacrificing behaviors were evident immediately (e.g., *self-blame* described below). Thus, *sacrificing* was a conscious action of taking responsibility to control the conditions that caused disequilibrium. Siblings believed that they could assist in regaining a sense of equilibrium, or at least avoid adding to the disequilibrium, by sacrificing.

Sacrificing involved two major inter-related processes that maintained each other, namely, sacrificing self and sacrificing childhood. Siblings believed that if they did not undertake these sacrifices, they would add to the environmental and emotional

disequilibrium that already existed. Sacrificing self is illustrated by four categories, *surrogate parent*, *surrendering parents' attention*, *emotional repression* and *self-blame*. Ultimately, these strategies led siblings to sacrifice aspects of their childhoods in that they became more *responsible*, *understanding*, *tolerant*, and *cautious* in everyday activities. Strategies associated with *sacrificing self* influenced personal changes associated with *sacrifice of childhood*, which in turn, maintained *sacrificing self*.

Sacrificing Self: Taking Responsibility to Restore Equilibrium

To restore environmental and emotional equilibrium siblings sacrificed their role as a sibling to become a *surrogate parent*. They also sacrificed any competition in the sibling sub-system by *surrendering parental attention*, and minimized further disequilibrium by *repressing their emotions*, all with the aim of regaining a sense of safety, security and control. A less conscious self-sacrificing strategy employed by some siblings to regain control over their sense of unpredictability and vulnerability was *self-blame*. These strategies and their sub-strategies are described below. The conditions under which these strategies operate and the consequences associated with them are also described.

The Surrogate Parent

Due to their injured sibling's vulnerability and the changed rules in the sibling sub-system, siblings could no longer interact with their brother or sister as they did previously (i.e., competition and sibling rivalry). Therefore, siblings found a new role for themselves in that of the *surrogate parent*. The surrogate parent role enabled

siblings to interact with their injured sibling within the confines of the new conditions. This role involved a deliberate attempt by siblings to regain control over the vulnerable condition of their brother or sister by taking responsibility to monitor, protect, and include them in their friendship circles.

In the *surrogate parent* role, siblings regarded themselves as part of the parenting “team”. They no longer saw themselves in the same league as their sibling with ABI, but rather identified with their parents. For example, one eighteen-year-old described how he and his parents looked after his sister following her accident three years earlier.

Her friends wanted to take her sky-diving three weeks after she got out of hospital. And *we* were saying no ... she didn't know what was best for her then ... *we* had to look after her....And then, *we* would have to lay awake when she stayed here for a few days because she would try and sneak out at the middle of the night and go in her car and drive. So *we* caught her a few times (ms18).

Similarly, another participant said, “As soon as this accident happened, *we* had to pull together and all be together to get Bill through ... and now it is still the same [because my brother is still ... not himself]” (ms17). Indeed, the surrogate parent role often began through an invitation by parents who modeled and instructed ways of navigating and managing the behavior.

Although this role was more dominant when the vulnerability of the injured child or family unit was perceived to be high, most siblings became socialized into the surrogate parent role over time and it became a more unconscious management strategy. The surrogate parent role is described in the concepts, *vigilant minder*, *altruist*, and *upholder*.

Vigilant Minder

The surrogate parent role was illustrated by the fact that most siblings became *vigilant minders*. Siblings vigilantly and constantly monitored their injured siblings' behavior in the hospital, at home, socially, or in any other situation that was perceived to present a high level of threat to their injured sibling or the equilibrium of the family unit.

For instance, to decrease the helplessness and vulnerability of their injured brother or sister, siblings took measures to be in *constant contact* with their brother or sister while they were in hospital. To achieve this, siblings sacrificed their own needs by giving up their daily activities, such as social outings, school, and sport. "I stopped going out and was at the hospital for eight weeks everyday. I would rather make him feel wanted and not hopeless" (ms16). Similarly, other siblings recalled a need to be with their injured sibling as often as possible. "Just before her accident, I was at school. But, that had a big effect on me -- her accident -- and I was at the hospital every day with her for three months ... every single day" (ms18).

I could go straight from school to the hospital, spend say half an hour with Marie, go to training and be back there [hospital] at sort of eight or whatever, when we finished, and stay there for an hour or so and go home. Other times I was pretty upset so I didn't feel like going [to training] so I just stayed [at the hospital] and just skipped a session altogether (ms18).

This contact reduced siblings' sense of helplessness and gave them a sense of control over the situation in that they perceived their presence to assist their brother or sister through the injury. These sacrifices were also perceived to assist in minimizing the vulnerability of their injured sibling by providing them with support and comfort.

I'd rather sit up there and see my brother everyday....You know, I don't want to go to school when my brother is sitting in hospital all day. I mean I stayed home one day you know, just to sleep all day and get a bit of rest and he got up and said 'Where's Mario? Get him up here!'I saw him everyday and everyone had a smile on their face, and that was just keeping him happy....I would just want to be up there with him and just help him through it all (ms17).

Although on one level constant contact reduced siblings' disequilibrium by providing them with a sense of control and inclusion, paradoxically it also increased their anxiety, highlighting further the extent of their sacrifice. Despite their discomfort and increased anxiety from exposure to the foreign hospital environment, siblings sacrificed their desire to escape the situation by making themselves available to mind their injured sibling, even if they did not want to. "I was just at the hospital every day and I'd go there, but I wouldn't even go in the room half the day. It was too sickening and that" (ms18). Thus, although constant contact provided siblings with a sense of control over their injured sibling's vulnerability, it also enhanced their anxiety.

Further, although constant contact made siblings anxious, escaping the situation resulted in guilt. One participant said that when he left the hospital he felt "guilty because I was walking out on my brother and sad because I didn't like what I saw" (ms14). Similarly, another sibling said "you feel like traitors leaving....At the end of the day, I remember feeling guilty, but I would be glad to go home" (fs20).

Despite being confrontational and resulting in turmoil and conflicting emotions, siblings perceived the needs of their brother or sister to outweigh their own discomfort, and they continued to sacrifice their daily activities, needs and desires by maintaining contact. Thus, vigilant minding in the form of constant contact assisted siblings to feel less isolated from the family unit as it increased their contact with parents. Constant contact also reduced siblings' confusion by fostering an understanding of ABI, helping

siblings to better *merge the familiar and unfamiliar*, because their contact with hospital staff and information about ABI was available. Siblings who had been protected from this environment were more likely to feel isolated, excluded and confused.

[Being involved in the hospital process] is better than nothing because it is good to be involved, but it is more stressful. Seeing someone ... in bed with tubes is shock[ing], but I'd rather see than be at home and not knowing what to expect (fs14).

The sacrifices siblings made for the well being of their brother or sister were not limited to the child's initial recovery period. Siblings continued to vigilantly mind their injured brother or sister by becoming *carers* and/or *protectors*. "I wasn't doing anything outside, around, I was just staying home with him, all the time" (ms13). Siblings took responsibility for caring for their injured sibling in everyday activities for many years. For example, seven years later, one male sibling stated. "[I] stay home with him, like we don't leave the house or nothing like that, just make sure he's alright....I look after him" (ms12). For some siblings, this long-term sacrifice centred around rehabilitation.

From [hospital] he went to physio and ... OT and speech therapy and that....And I still do physio with him and that ... we work together and then we did that for two years, just everyday for two years....Yeah [I helped with his program], I came most days and then that went on for five years... (ms13).

Siblings also constantly monitored and *protected* their injured brother or sister, especially in situations that presented potential for re-injury. Similar to the role of a parent, siblings assessed situations for their degree of threat, instructing their injured sibling's away from danger or intervening to protect them. Vigilant minding in the form of protecting, was driven by the motivation to control conditions that had potential to threaten the vulnerability of their brother or sister to re-injury or death, and

thus the equilibrium in the siblings' worlds. "I feel like I have to stand up for him so I always do....because I don't want him to die" (fs12). Some examples illustrate this role clearly.

I've changed towards him, that's the big thing, I used to just, wouldn't give a shit about what he did, I knew he could handle himself. But now, I have got to be on the [watch], anytime now I just look after him, watch what he does....It's all pretty much the way I feel just trying to protect him, because I don't want to have to go through that again (ms17).

I usually tell him to stop going that fast....Like if he is going with his wheel chair, I tell him to go slow and like go on the side of the road, and not go really far (fs10).

This strategy was related to the intense anxiety and worry siblings experienced as a result of their injured sibling's vulnerable health condition. In times of heightened anxiety, siblings were more vigilant and protective. Due to their injured sibling's enduring vulnerability, however, siblings felt compelled to constantly and vigilantly protect them. "...And like he went through a stage where he ... wanted to kill himself and you had to watch him all day every day in case he killed himself, and now if he gets really fired up he'll try..." (ms13).

The protector role also required siblings to protect their injured brother or sister's in the school-yard from cruel jokes and ill intentions. "He gets beaten up by this [guy], and I just go and help him, and just see the guy who did it, and I chase after him and hit him..." (ms10). Similarly, a female participant described how she protected her younger brother,

Me and mum were waiting in the car for him after school and at the lollipop crossing this kid pushed my brother around and called him [names] and I chased after him and I abused the living hell out of him ... I made it pretty clear to him....It happens and you like just want to get revenge for them (fs12).

In cases where siblings were not available to vigilantly protect their sibling, they employed the help of friends. “I look after him and protect him ... I try to always keep a view on him and if I can’t, I ask people to watch him or ask after him” (ms13).

The tasks associated with the protective role involved a significant *role change*. Even siblings who were younger than the child with ABI indicated that they now played the role usually adopted by the older sibling. One sibling who was younger than his brother with ABI said, “I became the bigger brother, I didn’t want him doing certain things because he could fall over and get killed” (ms17).

Although being protective was perceived to restore a sense of control over the vulnerability of the injured sibling, this strategy had potential to create more disequilibrium in the sibling sub-system. For instance, the children with ABI often resented taking instruction from their younger siblings. One sibling who was younger than her brother with ABI said, “He says I act in control and grown-up all the time” (fs14). Similarly, another younger sibling described, “Like I am the big brother sort of thing now. Like I don’t let him know that -- I can’t, ‘cause he’ll start a blue [fight]” (ms17).

Through trial and error, therefore, siblings learned to refine their actions so they could fulfil their need to protect their brother or sister and control disequilibrium. They learned to be subtle and deliberately conceal their actions in order to reduce the likelihood of conflict. Thus, siblings became highly skilled in exercising this role.

I try to look out for him as much as I can and help him, but he sort of gets the shits. Like if I try and do something for him, just to help him out and that, or, give him money, he’s like ‘I can get it myself’. The hardest times would be when I am ... just trying to help him. He will start throwing punches and what am I supposed to do? So I walk away and, that would be the hardest thing -just that he doesn’t want me to help him, even though he won’t admit that he needs it. He may not even need it but I am just worried, I am just doing the best for

him. You know how you say to your parents ‘Can I go out tonight?’, ‘No’, ‘Why not?’, ‘I am doing it because I love you, I don’t want anything to happen to you’. So I know how he feels, that’s why I try and keep it low profile. I try and do as much for him, but as little as possible you know ... just try and make it look like ... [I] don’t care, otherwise then he thinks that you think he is a baby, and he needs you to do all that (ms17).

Many siblings who employed this sacrificing strategy described their relationship with their injured brother or sister as being closer than it was prior to ABI. They had more contact and felt a sense of responsibility for their siblings that was not present before the ABI. However, this role was associated with *less reciprocity* and loss. “I am probably closer to Noah in a way that I always ... protect him a lot more, and so does mum” (fs15).

[I’m] more mature than her now. That’s how it has changed. It’s a bit upsetting actually ... the roles have changed a bit....[It’s] just difficult. It is hard to understand. You know, I’m thinking ‘geez, you should be the one saying this or doing this, instead of me, it’s your job’. It’s just hard to cope with....She must have just got closer to me and I don’t mind, I’m pretty close with her. Sometimes she gets annoying to me (ms18).

Thus, although vigilantly caring and protecting for their injured brother or sister provided siblings with a sense of control over the conditions that deemed them vulnerable, it perpetuated their feelings of loss and grief. Nonetheless, to continue to minimize potential disequilibrium, siblings felt compelled to sacrifice their own emotions for the well-being of their sibling.

Altruist

Another strategy applied by siblings in the surrogate parent role was that of the *altruist*. Siblings’ behavior was more consistent with that of a parent in that they sacrificed their natural tendency to compete and antagonize their injured brother or

sister and instead took responsibility for their wellbeing, often at their own expense.

“It just gets frustrating sometimes and she asks me to do something I just don’t want to do, I just do it anyway...” (ms18). In placing their *desires second* to their injured sibling and taking responsibility for their brother or sister’s wellbeing, siblings perceived them to be less vulnerable.

Siblings repeatedly extended themselves, doing things they normally would not do, for the well-being of their sibling. For example, one eleven-year-old boy said that despite his sister with ABI being annoying at times he still did what was best for her, even when he did not want to.

...when Mary and me went to [the water park] she was really full of energy and we kept on going on the same slide, even though it kept making me feel not too good. When I was going over it I thought it was amazing [that] Mary actually likes a ride ... I kept going [on] the ride but I kept on getting ... electric shocks when I was going down the ride ... I kept on going [but it was] ... stuffy so I couldn’t really breathe properly so that was also harder ... I enjoyed it for Mary, I liked going on it for about two or three times, but we went on it about fifteen times (ms11).

Another sibling described how sacrifices were made in all facets of their lives, including their personal and social lives.

For instance, if we are going after a woman and there is one there and two of us, I’ll let him go, I don’t want to even get in the way, you know what I mean? Like I want him to go for everything first, because I mean he would get the shits if he was after a chick and I grabbed her. But I just let him have what he wants and I take what ever is left... (ms17).

When asked if their generosity to their injured sibling was something that had always characterised their relationship, the siblings replied with statements such as,

No ... never, I mean if he came up and asked me for money [before the accident], I'd tell him where to go....[Now] I always look out for my brother and give him money whenever he wants. I mean it's money, who cares it's better than him going off and doing something stupid because he is depressed (ms17).

Another important task of *surrogate parent* role in the form of the altruist, was the tendency for siblings to include their injured siblings in their activities and *friendship circles*. "I try to include him in most of the things I do with my friends" (ms13). "Sometimes we go to the movies and stuff like that, when he has like got no one to go with, I like go with him or whatever, but he doesn't really go out that much" (fs14). Siblings were motivated to include their injured brother or sister in their activities and friendship circles in an attempt to make their life as "normal" as possible. Siblings believed that if their sibling was included in a group they would feel less emotionally fragile and depressed and, therefore, less vulnerable. Thus, siblings perceived that taking altruistic measures to minimize their injured sibling's vulnerability and compensate for their losses, reduced their vulnerability and minimized further threats to equilibrium.

The Upholder

As part of the surrogate parent role some siblings became *homemakers* and *mediators*. To achieve this task, siblings once again sacrificed time for school, friends, daily activities and homework to assume responsibility for upholding the equilibrium of the family unit. Siblings undertook household chores, cared for well siblings, cooked, and cleaned. One sibling who was thirteen when her brother was injured illustrated this.

He was in hospital for nine weeks and I was put in charge ... I was under control of everything, I had to keep the place alive and look after my little brother and sister ... I worked really hard and everything and I still had to do school....I think I went to school everyday in that 9 weeks except for one day when I went up to go and see him. And the rest of the time I was at school working and everything. [If I didn't] who would have looked after my little brother and sister? Like they were like the only people that I worried about... (fs14).

Similarly, another sibling who was only ten years old at the time of her sister's injury recalled,

There was a lot of responsibility put on me because she (injured sibling) was older than me....Like I had to look after her and make sure that she was like eating, and I made her lunch and stuff, and got her ready for school (fs13).

The surrogate parent role in the form of the upholder also included the tendency for siblings to employ conflict management strategies to *mediate* family conflict in everyday situations to maintain the equilibrium of the family unit.

Like sometimes when he gets into a rage or whatever I just like calm him down ... dad like, sometimes can't calm him down. So I just, can sort of calm him down a bit because he [listens to me] ... I just [say], 'settle down Ross' and he kind of like doesn't get so much angry and whatever at me (fs14).

Another strategy for upholding familial patterns in the home was *making up for losses* that resulted from the ABI. Siblings perceived that they were able to restore equilibrium by assuming roles lost following their brother or sisters' s injury. This concept is illustrated in an example of a sibling who felt responsible for replacing his brother's high achievement status in the family system. "With my brother [in hospital], it propelled me to study more and make up for what he lost. I felt for my brother and mum and dad because of their stress and I just wanted to relieve their stress" (ms18).

Therefore, in response to the loss of equilibrium siblings experienced following their brother or sister's ABI, siblings became surrogate parents in order to minimize their injured sibling's vulnerability, compensate for their losses, and maintain harmony in the home. In undertaking this role, siblings attempted to reduce the discrepancy between *the world that was* and the current world. In decreasing this discrepancy, siblings perceived that they had control over restoring a sense of equilibrium in the lives of their injured sibling, and thus, the family unit.

Data from the adult siblings suggested that the surrogate parent role, including the *vigilant minder*, *altruist* and *upholder*, had the potential to continue indefinitely. Although adult siblings were less likely to have daily exposure to the on-going conditions resulting from ABI, the awareness of their brother or sister's vulnerability remained and they continued to vigilantly mind, protect and sacrifice their time for their sibling.

I don't get actively involved in his life or sort things out for him. Although I do when he needs me to. And there are lots of occasions where something will not go right and I'll fix it up for him. I think I play now that sort of protective role too. To some extent. Not the same as mum and dad, but to some extent. I always buffer him against things ... bail him out (fs36).

Older siblings also worried about the long-term care needs of their brother or sister, and were willing to continue to sacrifice their needs to look after their siblings if they needed to. "The plans we keep continue to change ... I worry about if something happened to mum or dad - what would we do?...He's my brother, I should look after him if something happened" (fs20). Similarly, another adult sibling mentioned the growing concern regarding the responsibility of his brother's physical dependence when his parents pass away.

When dad dies or whatever, or gets too old to look after him ... it's a bit of a worry what is going to happen....It's such a worry like gee I don't know what is going to happen like when that time comes....[Dad] said it wouldn't be fair to like put him in my care because he said you have got to try and have like a normal life....You feel guilty honestly. You feel guilty [but] on the other hand you wouldn't want to take on that responsibility. It would be too much, it would be too hard and it would just affect my life in a lot of ways, that probably wouldn't be fair on me, but it's not fair on him either... (ms26).

Surrendering Parental Attention

Most siblings reported that their parents were often absent and employed *differential treatment* in favor of the child with ABI, resulting in feelings of jealousy, isolation, and rejection. The data, however, indicated that siblings justified their parents' behavior, sacrificing their own need for parental time and attention to accommodate the needs of their injured brother or sister. Siblings were cognizant of the extra needs of their brother or sister, who if not given extra attention, were perceived to be vulnerable to re-injury or death. Therefore, siblings perceived that surrendering competition for attention and parental time and resources was important for the well-being of their injured sibling and thus, the equilibrium of the family unit.

I am a part of the family but Blair needs, doesn't want, the attention, he needs it a little bit more and I am not counting. I know my parent's are still there and they love me. I mean, it doesn't matter what they show, I mean if they did the opposite, then because of the brain injury he might get depressed or, so they have to show him that....It's seeing him get help and he's happy so I'm happy and everyone else is happy (ms17).

Similarly, one thirteen-year-old sibling, seven years after his brother's ABI summed up the sentiment of most siblings when he said,

...mum and dad are like totally even with all of us, give us all the same attention sort of thing....Oh I've felt like that [left out] a lot but like I know deep down that I'm not left out at all, like sometimes I feel left out and that I am hard done by, but not a lot....When do I most feel left out? When he is sort

of getting all the attention, but I don't really feel left out. I know that he needs the attention because that's the way he gets through (ms13).

The siblings' *ambivalent emotions*, such as sorrow and empathy, embarrassment, guilt and disenfranchised grief fuelled their tendency to surrender to the inequity of parental attention. Siblings did not feel justified in complaining about the inequity. "You have to keep making yourself think [that] we can't lose sight for him ... he has stuck by us, there are so many chances he could've lucked out. He could have said, 'no, I give in...'" (fs20). This acceptance was also contingent upon siblings' exposure to the vulnerability of their parents. One thirteen-year-old said that she understood why her mother spoilt her sibling, "you can't really blame her [mother], seeing as though ... she went through a lot with it [ABI]..." (fs14). Siblings did not want to further burden their parents with problems by highlighting the inequity.

The siblings' willingness to sacrifice their need for parental attention was assisted by their understanding of ABI and the insight they had gained by merging the *familiar with the unfamiliar*. "I felt a little bit sad about that but I understood it though....Because James is sick and he needs more help" (fs13). "They were always worried about Sean ... like, of course they are 'cause he has been sick..." (ms14).

They had to look after Ross more and everything so it was a bit different ... because Ross kind of like needed full care ... not all the attention but you know what I mean, needed to be with someone... (fs14).

Emotional Repression

Despite the emotional turmoil they experienced following their brother or sister's ABI, including jealousy, frustration, anger, and embarrassment, siblings sacrificed their expression of this emotion in the sibling relationship and the family

unit. Their restraint was influenced by the immense sorrow and empathy they had for their brother or sister with ABI, the guilt they felt about still being able to do activities their brother or sister could no longer do, and the disenfranchised nature of their grief that prohibited them from acknowledging their emotions as legitimate. Siblings' awareness of ABI and their ability to *merge the familiar and unfamiliar* further prevented them from expressing their own emotion. Instead, siblings sacrificed the expression of their negative reactions and repressed their feelings, either accepting their situation or simply *withdrawing* from it. This category is illustrated by the concepts of *restraint* and *secret silence*.

Restraint

As previously highlighted, siblings were constantly mindful of their brother or sisters' vulnerability, which had implications for the sibling relationship in that siblings were less expressive in their contact. "[We don't fight] as much as we used to because he only had one arm to fight, so it was a disadvantage..." (ms14). Siblings refrained from physical fights or activities with their injured sibling so that they did not injure them further and cause more disequilibrium. "I would never get physical with him if he annoyed me because I don't want to hurt him anymore than he already has been" (ms13). Thus, siblings often avoided physical conflict or *escaped* from situations rather than entering into conflict. This form of sacrifice was illustrated in the following examples.

I can't, I've hit him once but I can't because there's a bit of skull missing on his brain and if my knuckle gets in that, he could be dead or have a big brain injury or something. So it's not worth it. When we fight I just walk away ... I just sit there and say it's not worth it (ms17).

Well he is still the same as he was but like we are more careful with him and that....We kind of just not be as rough and that....Because I don't want to hurt his neck or anything again ... I didn't usually like touch his neck except I'm more careful now, I keep away from him (fs13).

I ... just feel like smacking him, you know in the head, but I can't.... Sometimes I would forget that ... a plate was on some side of the head and I would accidentally hit it ... That's why I don't hit him, I will just punch him sometimes (fs12).

The siblings believed that they had control over their injured siblings' recovery.

"You can just see her improving everyday, so it was good to see and that's why I thought well if I keep, you know, not annoying her and that, she'll get even better and she has got heaps better" (ms18). When siblings did not exercise restraint, they experienced guilt, which heightened their emotional disequilibrium. "Accidentally ... a few weeks ago, I smacked him across the head and [I felt] guilty ... because I made him cry and usually I don't make him cry" (fs12).

Siblings described sacrificing the expression of their emotions mostly to maintain the peace and harmony in the family unit. At times of heightened turmoil, the injured children were more likely to be antagonistic, creating an even greater need for sacrifice as highlighted by the following participant.

Some things he doesn't get and he thinks he's right and you have just got to agree with him, but it is like hard because he is not right kind of thing and he gets like angry easy and stuff so ... we don't really fight that much....It is [frustrating] because he thinks that he is right and stuff and you know he is not and he is really persistent at you, like you know, keeps going on and going on and he doesn't accept that he is wrong. Like he doesn't even know he's wrong so you just have to agree with him but that's like hard....He gets so like up in arms and angry ... so you just have to [say] 'Okay you are right'....[It's] kind of hard because like even if you're right, you still have to [agree with him]....I just go 'Fine, fine'....Because you can't really say much because like he doesn't get it (fs14).

Siblings also refrained from verbal arguments to reduce the risk of contributing to their injured sibling's emotional vulnerability. Refraining from conflict also managed the loss of further emotional equilibrium for siblings.

Try and bite my tongue now if I am going to argue with her....And, that is just by common sense really, because if you upset them, upset her, you don't know what they are thinking ... it's awful to say, but even suicide....Just have to say, you just have to put up with it as best as you can ... try not to aggravate them because otherwise it gets [you] upset. And, just bite your tongue even if you are in the right, you are better off just biting your tongue, it is a lot easier in the long run, even if you are right, just swallow your pride (ms18).

Some siblings indicated that parents reinforced their belief that it was necessary to withhold their behavior and repress their feelings. "It feels a bit weird because he's wrong and I have to go with it....and I am not allowed to argue with him" (ms12). It seemed that the *parental input* (see navigating) was another factor that influenced siblings' tendency to sacrifice. "Mainly through dad [I learnt]. I try to bite my tongue now if I'm going to argue with her" (ms18).

Secret Silence

Many siblings confirmed that they had not talked to anyone, especially parents, about their thoughts, feelings or concerns regarding their injured sibling or the implications of their injury. In some cases, this study was the first time siblings had talked about their brother or sister's ABI. "I don't talk to family about nothing like that or mum and dad, I'm not close like in that way" (ms18). One twelve-year-old sibling who was five when his brother sustained an ABI revealed in the interview, "this is the first time I have talked about it" (ms12).

There was a clear relationship between the siblings' awareness of their *parents'* *vulnerability* and the repression of their own feelings as part of their quest to take responsibility for the well being of the family. "I saw how sad my parents got and I just wanted to cheer them up sort of thing" (ms13). Siblings kept silent about their feelings and concerns because they did not want to further contribute to their parent's burden. For example, when asked to choose a facial expression that best represented his feelings, one fourteen-year-old picked an expression and said, "It sort of looks like feeling sad, but trying to hide it so your parents don't worry..." (ms14).

In hiding their emotions, siblings assumed responsibility for supporting the family. As one sibling who was seventeen years old at the time her brother sustained ABI said,

It was hardest talking to mum then ... I didn't want to upset them [parents]....Everyone always said to us [two non-injured siblings] 'you guys have to be strong for your mum and dad', and I was Yeah, [thinking that] I have got to be strong for mum and dad. So I didn't want to talk to them. I talked to mum about it ... [but] not so much dad because he did get upset ... you don't like upsetting your parents....I wanted to look after mum and dad, but to do that you have to be in control of yourself first....[My other brother and I] were the supporting members of the team we just have to check up on everybody because we had been told to check up on mum and dad (fs20).

Another participant who was seventeen years of age indicated that he too kept his feelings silent so as not to upset his parents and to assist his family to feel less vulnerable.

The worst part is looking at my parents when all that was going on ... I'd see them and I'd get upset....If they [parents] see you crying ... then they are going to get upset for you. So if you try and you know, you try and keep the spirit going and walk in everyday and say, 'how are you going...? Looking good'....You make yourself happy ... see then everyone has got a good vibe in them [and] everything should be alright (ms17).

As evidence of the success of this sacrifice, the hospital staff and parents who were interviewed believed that siblings were largely unaffected by the ABI. In contrast, the data indicated that they were significantly affected by this experience, but did not want their parents to know. Clearly, sacrificing the expression of their emotions was a conscious strategy siblings used to prevent adding to the vulnerability of their parents.

The siblings' experience of *disenfranchised grief*, however, also influenced their tendency to refrain from confiding in others about their feelings. Many siblings indicated that they would have liked the opportunity to discuss their feelings with someone, but did not feel justified, since they were the *lucky ones* who were left uninjured. One male participant said, "Yeah, there would've been [times when I wanted to talk about it], but I was too embarrassed" (ms18). Even when they wanted to talk to someone about it, many of the participants still avoided doing so. "I have never liked the thought of, you know, talking to somebody. I suppose I just kept it to myself and, you know, worked it out or whatever" (fs14). Others said they just "...don't like talking about it" (ms12).

In addition, the data indicated that the initial strategies employed by parents to manage the situation, also contributed to how siblings coped with their emotions. When parents did not discuss the situation with siblings, siblings perceived such discussion to be undesirable, especially as they witnessed how upset the situation made their parents. Consequently, a *code of silence* emerged within the family.

My parents didn't really talk, I really wouldn't know what they got told. I think they were left in the dark for a bit until he stabled [his condition became stable], and then, it was sort of coming out but I didn't have anything [to do with it]....My parents did all that [talked to doctors in interviews] and they didn't talk about it to me....They didn't really share (ms17).

This code of silence extended to the reluctance of siblings to ask their parents for ABI related information. Siblings indicated that instead of asking their parents for information, they “just waited” (fs13) for parents to initiate conversation. When this did not happen, the code of silence was reinforced. Some participants avoided asking their parents for information because they feared that they would be over-stepping the rules. For example,

When I asked my mum I thought she would have been like ‘Oh so you want to know now’, and then she would have had me sit down and then we would have had like this big lecture, it makes me sad (ms13).

The code of silence continued, even into adulthood, as illustrated by the following adult sibling.

I can’t really remember having a discussion about it years ago when it first happened, but we did talk about it later on a little bit, but they don’t tend to talk about it too much....I don’t think I coped with it all that well because I bottled it all up, turned everything inward rather than speaking to people about it. Whether that is a good thing or not, I don’t really know, but it depends on the type of person you are I suppose (ms26).

This sibling indicated that this way of dealing with grief -- bottling up and shouldering responsibility to be strong for others -- became the normal way of coping throughout his life.

Whether it was from [the accident] or just naturally inherent -- I can deal with tragedy fairly well. Like, my grandmother died last year and that was very difficult ... I was sitting [in the funeral] going ‘I am not going to cry, I am not going to cry’ and I didn’t end up crying....I am sort of like a rock like that, I can help people through it (ms26).

Although silencing their emotions was perceived to minimize *familial turmoil* and *parental vulnerability*, it increased siblings’ emotional disequilibrium in that their

frustration and anxiety was not expressed. When asked what they did and still do with their feelings, such as worry, participants replied “Nothing much....Keep it to myself” (ms14), and “I sort of bottle them up and get stressed out over it sometimes” (fs14). “When it happened I like didn’t want to talk about it or anything ... I keep it to myself like when I am upset...” (fs13). One participant who blamed himself for his sibling sustaining ABI, still “...didn't talk to anyone about it” (ms18).

At the other extreme, a less common strategy implemented by a small number of the siblings interviewed was *emotional expression*. Expressing their emotions was described as useful for releasing emotional tension and increasing a sense of emotional equilibrium. Siblings said that it helped to “get it out” (ms14). Due to the disenfranchised nature of the siblings’ emotions, however, emotional expression was most likely to occur under the condition that it was invited, by parents or friends, and was perceived to be permitted. “My parents told me how they felt and I told them how I felt and that helped me to talk” (fs12). Similarly, another participant said, “mum and I have a lot of deep conversations about it [which] helped a lot”. One adult sibling confirmed the need for the expression of emotion regarding ABI.

Looking back at it, I get, and still do, get frustrated with mum and dad because they don’t see the changes in him or they don’t talk about it....It wasn’t necessarily good for me....I often made bad choices about who to mix with and I think a lot of it came from the desperate feeling of loneliness ... it definitely changed me and it needed to be talked about (fs35).

Emotional expression, however, was a *catch-twenty-two* for siblings because expressing their concerns and emotions had potential to result in further anxiety and guilt if they perceived the conversation to threaten their parent’s vulnerability. Thus, siblings described employing more subtle strategies that helped them to express and

resolve their concerns, without feeling as though they were burdening others. For instance siblings employed the strategies of letter-writing, journaling or talking to close friends and teachers rather than family.

I needed to just tell someone but I didn't want to tell anyone. I needed to think what I wanted to say to myself so I wrote myself a letter I [wrote about] feelings that I was having....To write that letter [helped me] realise what it was I was feeling, because it was so ambiguous, why you feel like crap some days and why you feel good on other days....Being able to write that down and write down those feelings and then four years later [read it] and [see that] I've really ... come a long way ... I think you wouldn't think about it or recognise that if you didn't journal it (fs20).

I wanted [to talk to someone about my feelings] ... but I would have felt [strange]. I didn't want to, it's hard to explain. So that is probably when my diary started....I write in my diary and figure out how to sort it out and then do something about it... (cfs15).

Talking about anything helps so it did help you know always having someone to talk to and friends are more than willing to help. [It's easy to] think that it just burdens them but it doesn't. They're always willing to talk when you need it....I spoke to some of my teachers so they were really helpful....They sort of made it so that I felt like it was a normal thing to go through, normal feelings to go through when something like this happens (fs14).

These strategies helped siblings to process, "normalize," and acknowledge their feelings. Hearing others' stories about being a sibling of someone with ABI (see member checking, Chapter 4) also assisted to normalize the siblings' emotions. The normalization countered the impact of *disenfranchised loss and grief* as it legitimised siblings' feelings and assuaged their guilt for feeling such emotions. Expressing emotions was, therefore, an effective strategy for regaining emotional equilibrium.

Self-Blame

Self-blame was another strategy that siblings employed to regain a sense of predictability and control in their vulnerable world following ABI. Unlike the strategies presented above, self-blame as a strategy to regain equilibrium was an

unconscious process that appeared to be triggered from the onset of ABI for most siblings. “Blaming yourself, I think its just natural that you feel guilty because something’s happened and you had no control over it” (ms13). Taking responsibility for the ABI was the ultimate form of self-sacrifice that resulted from siblings’ belief that their actions had somehow caused the accident or illness. The direct responsibility siblings placed on themselves was evident in their words, for example, “[I felt] ... guilty that I accidentally hit him on the butt or something and that pushed him out of the window...”(ms14), and “I blamed it all on myself ... because I could have done something to have prevented him from hitting [his head]” (fs12).

As illustrated in the previous chapter, many siblings experienced intense anxiety associated with exposure to the unforeseen, mortality, and ultimately, the vulnerability and unpredictability of their assumptive world. This exposure led siblings to search for a meaning behind such a random event. Understanding the event and finding a meaning in its cause, through the strategy of self-blame, made the ABI appear less random and thus, restored a sense of predictability and control in the siblings’ world. Thus, research regarding the significance of self-blaming attributions to control the future was incorporated into the concept of self-blame. For instance, some researchers have proposed that by adopting the illusion of personal control in the present or past, a self-blaming attribution could enhance perceptions that negative events in the future could be prevented, thus protecting the belief that the world is reasonably kind, meaningful and predictable (Janoff-Bulman, 1979; Janoff-Bulman & Wortman, 1977). Perceiving the past to have been controllable leads to the logical conclusion that the future can also be controlled, thus enhancing feelings of empowerment and decreasing vulnerability.

Because children are “limited by experience, not by logic” (Murray, Farley, & Wilson, 2002), many of the siblings believed that their sibling’s ABI was their fault when no other reasonable explanation was available. As highlighted in the following example, siblings searched for a meaning to explain the event. When no explanation was available, they found one through “logical” deduction.

...It felt like the accident was all because of me because ... if Mary hadn’t have been following me, and if we had have been wearing our helmets, everything would have been at least a little bit better or it wouldn’t have happened ... I realised that because I thought I was the only one around. I thought who else’s fault is it?...Besides if we were wearing helmets then it could have been a little bit better...(ms11).

Siblings who witnessed their brother or sister sustain ABI were more likely to blame themselves and take responsibility for their sibling’s ABI despite having no control over the event. However, even siblings in the vicinity of the accident or who believed their behavior to have somehow contributed to the lead up to the ABI also blamed themselves for their brother or sister’s ABI. One sibling blamed herself for not being able to prevent her brother’s injury.

I started to think it was all my fault and then I remember I kept thinking I wish it had been me, if he had been riding my horse instead of his, because my horse was [quiet]. Like I might have said ‘just take mine’, all those sort of fortune questions (fs20).

Similarly, other siblings said “we were going fast and I was going to ask the driver to slow down and I felt bad because I didn’t ... I think about it ... I wish I had said something” (ms17). Even when the accident or injury was unarguably the result of someone else’s behaviour, siblings blamed themselves. For example, siblings whose brother or sister was hit by a car while crossing a zebra-crossing, injured in an accident caused by an intoxicated driver, or even experienced an aneurysm, still

blamed themselves for the injury. This sense of responsibility is illustrated by a sibling who flipped a coin with his sister for the use of an umbrella. When his sister lost, she ran ahead to get out of the rain and, in doing so, was hit by a car. “Actually at first I was pretty angry at myself for taking the umbrella back off her because she like, might have walked with me, if she had the umbrella...” (ms18). One sibling whose brother suffered an aneurysm lamented, “[I wondered] why I couldn’t stop it or help my brother, I think about it all the time” (ms14).

Similarly, a sibling whose brother was injured when the bus they both were in was hit by a reckless driver blamed herself for not being able to control the accident. As a result she took measures to prevent the accident from happening again.

I blamed it all on myself ... if I hadn’t have had my head in that book [that I was reading when the accident happened]. I could have like sat next to him in the bus, you know, and not been reading at the time and, you know, just like keeping my eye on the road....Months after the accident we went back onto a bus...and I made him sit next to me and I made sure that I had my eyes on the road (fs12).

By understanding the event, and having a reason for its cause, siblings believed that they could prevent it from happening again, and took measures to restore a sense of predictability around situations that were perceived to be threatening, such as driving on the road.

In this regard, Janoff-Bulman’s (1992) hypothesis regarding the various presuppositions made in the assumptive world also fits with the theory that siblings blamed themselves in order to restore a sense of control and prevent such events from happening in the future. According to Janoff-Bulman (1992), the assumptive world includes three fundamental presumptions: that the world is kind, the world is just and meaningful, and the self is worthy. According to these beliefs, being “good” protects

individuals from loss and dreaded events. An adverse event, such as an ABI, however, may force “good” people to relinquish this belief, threatening their sense that life is predictable, meaningful and controllable (Murray, 2001a). As highlighted in the previous chapter, the adverse nature of ABI forced many siblings to abandon their belief that the world is controllable and meaningful. Relinquishing this belief, however, may have been too threatening for some siblings who preferred to “make harsh moral judgements about themselves” (Murray, 2001a, p. 231) rather than perceive the world as uncontrollable.

Indeed, the data suggested that if siblings perceived themselves to be doing something wrong, such as riding without a helmet, not sharing umbrellas, or smacking or arguing with their brother or sister before their injury, they were more likely to see the accident as *punishment* for that “wrongful” behaviour. This allowed them to maintain the belief that the world is predictable, just, and that bad things only happen to people when they deviate from the “rules” or are *bad*. For example, one sibling believed her brother’s ABI to be her punishment for a fight she had with him prior to his injury.

...I don’t really like saying this but you know ... because on the afternoon of the accident he (injured sibling) wasn’t doing as he was told, you know I told him to wait inside the school gates and after that I gave him a little bit of a smack across the back and ... you know, that’s the reason why I blame myself a bit you know if I hadn’t of smacked him, this wouldn’t have happened. Because you know this was my pay back for hitting him ... like inside I was feeling guilty... (fs12).

Some siblings said that over time, as their brother or sister recovered, they blamed themselves less. “I learnt that it wasn’t my fault, my parents and brother told me that it wasn’t my fault ... [what helped me to get over the guilt] was seeing that he

is okay and him saying that it wasn't my fault" (fs12). Many of the siblings who blamed themselves for the incident, however, indicated that they continued to doubt their innocence for many years following the event, even in light of evidence to the contrary. Nor did the feeling of self-blame always diminish with time as indicated by one sibling who witnessed his brother fall seven years previously.

I still tend to [blame myself], it's silly, but you know I don't do it as much anymore, but I used to all the time. Yeah people try to tell me [that it's not my fault] but I don't listen to it. Like I don't really think it's, I sort of do and sort of don't you know....Mum and dad said it was an accident (ms13) .

Reassurance from significant others, or *emotional expression* of their emotions did not always alleviate the siblings' sense of responsibility. Further, although the strategy of self-blame to control the vulnerability of the world may have afforded siblings a sense of control over the random nature of the world, this strategy enhanced their sense of *emotional turmoil*, increasing their sense of responsibility.

Given that self-blame was an automatic process that siblings employed from the ABI onset, it often occurred in unison with the other sacrificing strategies, and in fact, reinforced these strategies. The sacrificing strategies above were additional ways of controlling their sense of vulnerability and guilt resulting from self-blame.

At the other end of the continuum, however, some siblings attributed blame to other people believed to have been responsible for their brother or sister's injury, such as drivers of other vehicles, or doctors caring for their sibling. "[I] am pretty mad at the driver ... I want to go back and [beat] the driver" (ms17). Similarly, another sibling whose sister acquired damage to her brain through a simple operation recalled, "[I was] angry at the doctor....I wanted revenge on the doctor" (ms13). Despite

attributing blame externally, rather than internally, the strategies of self-blame and blaming others both aimed to find meaning, control, and predictability.

Sacrificing Childhood: Personal Change Resulting from and Maintaining Self-Sacrifice

Not surprisingly, a major life-altering event such as an ABI, and the life changes it demanded resulted in siblings experiencing ongoing personal changes. As illustrated above, ABI required siblings to make many sacrifices in order to regain a sense of equilibrium in their worlds. The data indicated that these self-sacrifices, resulting from the siblings' exposure to ABI and its many associated losses, influenced siblings' personal development. For instance, siblings believed that compared to their friends, they were more *responsible, understanding, tolerant, and cautious* in everyday activities, directly as a result of having their brother or sister sustain ABI. "It is a big thing to go through and you grow up quickly and have no choice really" (fs14). Interestingly, these personal attributes appeared to maintain siblings' tendency to self-sacrifice.

Responsibility

Following ABI, many siblings no longer had the opportunity to experience childhood egocentricity. Indeed, they made many sacrifices in order to take responsibility for the well being of their family. Thus, siblings described that they "just got more responsible with things, with heaps of different things" (ms18). One fourteen-year-old participant said,

I suppose I have become like more independent, having mum not there or whatever, I have kind of had to look after myself a bit more ... kind of like grown up a bit I suppose, like having to deal with so [much] of Ross' stuff, so yeah... (fs14).

Similarly, another fourteen-year-old female participant said, "I think that I have changed in some ways. Like maybe I'm more responsible 'cause I looked after every one when Jerry was in hospital, so I grew up a lot" (fs14). Many siblings felt that if they did not exercise responsibility and restraint, the threat of returning to turmoil was ominous. The responsibility siblings shouldered for the well being of their family, and the sacrifices they made to do this, therefore, became a life-long pattern as evidenced by one sibling twenty years post-injury.

[My brother with ABI] is somehow released from all those social bonds....He knows all his manners and he knows how to behave, but he will belligerently choose not to....[So] I'm supposed to be the responsible one ... I feel like I can't cop out of those rules because who is going to do it then? *What will that do to mum and dad, you know?* So there is a sense of responsibility I have developed. I mean it may have happened anyway, that's the difficult thing, you just don't know whether it would have happened anyway, but I don't think so. I feel very much at this point as though I was forced to carry the role for both of us, really. Because it was clear that he wasn't going to (fs35).

Understanding

Siblings reported that as a result of their brother or sister's ABI, they also became more understanding of disability and empathic towards people less fortunate than themselves. One sibling said that he had become more sensitive to other people "...probably caring ... because before it happened I never cared for anything. Now, I don't know why, I just don't want to hurt people's feelings" (ms14).

If people are a bit mentally slower in any way ... I can understand them more now, like I just don't laugh behind their back or anything. Like I'll talk to them and that, I'm not scared to talk to anyone. So, that has helped me a bit (ms18).

One sixteen-year-old female sibling stated that her sister's ABI had opened her eyes to the world and that she felt less naïve about certain issues in her life. She said,

We hadn't been out there, we hadn't seen the world ... but you get into hospital and there's these little kids and it sort of hits you. Other people are in our situation so we shouldn't be so self-centred and think it's only us. Like you sort of have to, we now have an understanding of what those people have gone through, of what people are going through now... (fs16).

Siblings reported that they became more understanding of people generally and saw this as a positive consequence of their brother or sister's ABI.

I think I am a lot more understanding and mature than most of the people I know. I don't really judge people a lot. I never really have. It makes you understand a lot more and it does teach you a lot of things like tolerance, patience, all those sort of things. You learn to treat -- just because they look different or they are different -- you learn not to treat them much differently (cfs15).

As illustrated above, this increased understanding of ABI was learnt through *maturation, navigating* and *sacrificing* processes. This understanding then assisted siblings to merge the old and the new and integrate the continuing changes into their lives, which often reinforced self-sacrificing behavior.

Tolerance

For siblings, the sacrifice of their expression of emotion in the face of frustration required tolerance, which further assisted them to sacrifice. As illustrated in the following example, siblings adapted to their situation by sacrificing their childhood and learning maturity and responsibility.

It was hard because he would break a lot of your stuff, like he broke one of my tennis racquets once, like not meaning to, like he would just get it and he was walking with it and he fell over and hit it into the ground and broke it. And then, that's sort of hard when you are a kid and you've got this thing you really

prize, it's your pride and joy and he accidentally breaks it....And then what can you do? You can't [yell]....That leads to the tolerance thing like ... you just learn, it teaches you to put your stuff up out of his reach you know, and as a kid that is probably a good lesson to learn, you know? (ms26).

Indeed, all the siblings described themselves as “more tolerant” (ms18) after their sibling sustained ABI. “I don't remember before but now like you just have got to be like patient and ... I suppose it has made me more tolerant...” (fs14). One ten-year-old participant said her patience had increased “because I have been with Max for a while now ... you have to have real patience for him to talk” (fs10). This patience and tolerance resulted from sacrificing strategies and became an essential virtue for continuing sacrificing strategies.

Cautious

Siblings also sacrificed momentary pleasure in that they became more cautious about engaging in certain behaviours. Siblings no longer had the carefree recklessness that they may have had prior to their exposure to the vulnerability of life and their maturation process was accelerated as a result. For example, an eighteen-year-old sibling said that since his sister's car accident in which she sustained ABI, he was much more cautious when driving.

It [sister's ABI] has just made me understand a bit more about accidents and being stupid and doing stupid things, like in cars and that with friends and that. Like if they are driving hoons and that, I always tell them you know 'slow down a bit'. And, everyone should go to a hospital and see what happens from car accidents and that before they get their license ... things like that....I stick to speed limits, do everything right, don't do nothing stupid. Only because of that factor. I think I would have been different if she didn't have the accident to tell you the truth. So that was good and that's another positive (ms18).

One thirteen-year-old female participant whose sibling had a stroke after going on a theme park ride said, “I just don’t go on roller coasters and that ... just in case, and I don’t like them anyway, but I think it might happen to anyone” (fs13). Similarly, another thirteen-year-old male said, “Just taking more care with injuries that happen to people, or injuries to myself, I don’t push myself that hard anymore” (ms13). When asked if he had changed since his sister’s ABI from a fall from a bike, one eleven-year-old male said,

I never forget my helmet ... I do feel I have changed since the injury, and I am a lot more careful now and Mary makes sure, and I make sure, whatever I do is going to be safe, safer than what happened on the injury ... I am really scared (ms11).

The young age of the siblings from which these comments come reinforces the childhood sacrifices siblings made to accommodate for the changes in their injured brother or sister and to control the perceived vulnerability of their world. The siblings’ increased responsibility, understanding, tolerance and caution that was influenced by exposure to vulnerability and the employment of self-sacrificing strategies consequently maintained the self-sacrificing cycle.

Summary

In summary, the BPS process that siblings employed to manage the continuous loss of environmental and emotional equilibrium was *regaining equilibrium*, as illustrated through the processes of *navigating*, *sacrificing self* and *sacrificing childhood*. Although distinct, these processes often occurred simultaneously and shared a common purpose of restoring a sense of safety, security, predictability and control. Although the degree to which these strategies were exercised was contingent

upon on the geographical proximity of siblings to employ them, many siblings indicated that they lasted into adulthood, even when they moved away from the family unit.

Navigating illustrated some of the strategies that siblings employed to integrate the evolving disequilibrium into their lives. For instance, as conditions relating to the child with ABI changed, the siblings employed strategies such as, *challenging new rules with old tools*, *withdrawal*, *trying and buying*, *merging the familiar and the unfamiliar*, and eventually *integrating*. All of these strategies aimed to restore equilibrium, however, some of these strategies were more useful than others. Typically, siblings continued to employ strategies that were perceived to be successful in reducing vulnerability and emotional turmoil and discarded those that had the inverse affect.

Most strategies that were perceived to be useful in minimizing vulnerability and emotional turmoil were self-sacrificing strategies, such as, *surrogate parent*, *surrendering parental attention*, *emotional repression* and *self-blame*. Many of these strategies were learnt through the process of navigating, however, some were employed from the onset of the ABI. The employment of sacrificing strategies was contingent upon siblings' belief that their behaviour had the ability to restore predictability and control and to minimize vulnerability. When siblings perceived new situations to be beyond their control they often *withdrew*. When sacrificing strategies were perceived to cause disequilibrium, they were refined and modified through the navigating process. Although sacrificing strategies were perceived to be the most useful strategies for regaining environmental and thus emotional equilibrium, they had potential to increase siblings' emotional turmoil. Often, however, because siblings

perceived the needs of their injured brother or sister and their family to be of greater importance, they sacrificed their own discomfort to maintain the equilibrium in the family unit. Although a less common strategy, some siblings regained a sense of emotional equilibrium through *emotional expression*. The ultimate form of self-sacrifice was illustrated in the strategy, self-blame. This process appeared to be employed from the onset of ABI and was another factor that maintained siblings' tendency to self-sacrifice and take responsibility to provide safety, security, predictability and control. This strategy was motivated by vulnerability and guilt that in turn perpetuated siblings' emotional turmoil.

Exposure to the vulnerability of the world and the responsibility that siblings displayed through *navigating* and *self-sacrificing* ultimately led siblings to *sacrifice their childhoods*. Siblings described that as a consequence of their brother or sister's ABI and the many losses they endured as a result, they developed personally, becoming more *responsible, understanding, tolerant* and *cautious*. These qualities fostered insight, maturity and selflessness, which maintained siblings' tendency to employ self-sacrificing behaviours.

CHAPTER 7

CONCLUSIONS AND IMPLICATIONS

The current study developed a grounded theoretical framework for understanding the impact of an ABI on siblings. This framework proposed a set of integrated categories, concepts, hypotheses and propositions about the main issues of concern for siblings and how they managed these concerns. This study found that the impact of pediatric ABI on siblings was profound and that managing this impact involved a set of complex processes unlikely to be identified through positivistic or descriptive methods.

The findings suggested that pediatric ABI was a life-altering event for siblings, who as a result, experienced a loss of environmental and emotional equilibrium. Siblings were exposed to a variety of conditions that threatened the predictability of their *assumptive worlds* (Parkes 1975). These conditions highlighted the siblings' sense of vulnerability and challenged their sense of security, safety, and control. Specifically, siblings were exposed to the unforeseen, the near mortality of their injured sibling, the on-going unpredictability and fragility of their brother or sister, and the vulnerability of their environment. Siblings were also exposed to major changes within their family unit, in that they experienced an emotional and physical absence of parental attention, differential treatment, and a loss of belonging. Siblings perceived that, as a result of the ABI, their family experienced enormous turmoil, and their parents became emotionally vulnerable. Not surprisingly, siblings experienced a loss of emotional equilibrium, which was manifested as emotional turmoil, and ambivalent emotions, including anxiety, jealousy, annoyance, embarrassment, sorrow, empathy, guilt and disenfranchised loss and grief. Due to the non-finite nature of an ABI, this

loss of environmental and emotional turmoil evolved, reappearing repeatedly over time.

Given the enduring losses resulting from an ABI, siblings were motivated to take responsibility to regain equilibrium in their worlds. Through the process of *navigating*, siblings employed strategies that assisted them to negotiate the enduring disequilibrium. These strategies included *navigating new rules with old tools*, *trying and buying*, *merging the familiar and unfamiliar* and *integrating*. Siblings also employed *self-sacrificing* behaviors that required them to place their needs and desires aside in their everyday lives. Siblings sacrificed their role as a brother or sister to become surrogate parents. They sacrificed their right to parental time and resources, their expression of emotion, and their innocence in the form of self-blame. Like the non-finite nature of an ABI, sacrifice was on-going and constantly modified through the process of navigating. Ultimately, these sacrifices resulted in long-term personal changes for siblings as they sacrificed aspects of their childhood, and as a result, became more responsible, understanding, tolerant and cautious. These personal changes then appeared to maintain the siblings' continued use of sacrificing strategies in an attempt to restore equilibrium in the face of subsequent challenges.

The findings of this study are significant for several reasons. First, components of the framework confirmed, contextualized and linked similar constructs found in the literature on siblings of children with an ABI and other health conditions. It also extended literature regarding the impact of an ABI on family members, which usually focused on parental reports. In addition, the theoretical framework supported previous literature regarding family adjustment to an ABI and other non-finite loss. Specifically, the adjustment process identified in this study was complex and cyclical

and the findings suggest that siblings may experience a process of recurrent loss and adjustment. Thus, the study provides a coping and adjustment process that could apply to many situations of loss.

Second, the theory provides a depth of understanding that has not previously emerged from research in this area. Although some constructs in the theory have been identified in previous research, the current study provides a development of these concepts to a meaningful level that will enhance understanding of siblings' experiences.

Finally, the current study provides a comprehensive yet parsimonious model that provides clarity and coherence to an area that has traditionally been discrepant and disjointed. The model proposes hypotheses that may account for many variations and inconsistencies found in previous research.

This chapter first discusses the significant contribution of the current study in relation to the confirmation of previous findings, the deepening of theoretical knowledge, and the clarification of discrepancies in previous research. The quality of the theory is also reviewed and the implications of the findings for future research and practice are discussed.

Confirming and Extending Previous Findings

Individual components of the theory identified in the current study confirmed and extended previous literature that explored the impact of an ABI and other health conditions on siblings. The framework also confirmed and extended models of family adjustment to an ABI, by providing the sibling's perspective, which often goes unconsidered in research and practice. The siblings' adjustment to an ABI is similar to

those identified in the literature on ABI and other non-finite losses. These issues are discussed below.

The Current Model Applied to Previous Sibling Research

The current study confirmed previous findings that an ABI is an event that renders siblings' worlds "forever different" and that their lives continue to be impacted for many years post-injury (Gill & Wells, 2000; Orsillo et al., 1993; Willer et al., 1990). The current study also confirmed anecdotal reports (Kneipp, 1996; Maurer, 1991) that the onset of an ABI results in immense emotional turmoil and change for siblings. However, one of the major contributions of this study is that it provided an important and comprehensive theoretical framework within which most constructs identified in previous research can be integrated, linked and contextualized. This theoretical framework included concepts that were similar to constructs identified in previous descriptive studies regarding the long-term and systemic impact of an ABI on siblings.

Components of the categories, *vulnerability of life* (i.e., vulnerability of injured sibling), *vulnerability of the family unit* (i.e., family turmoil), *emotional turmoil* (i.e., anxiety, worry, ambivalent emotions, and loss), *self-sacrificing* (i.e., surrogate parent, emotional repression), and *sacrificing childhood* (i.e., personal change), confirm similar themes in previous literature (Gill & Wells, 2000; Peretti & Abderholden, 1995; Willer et al., 1990). For example, Willer et al. (1990) identified family stress, changes in family lifestyle, concern for the injured sibling's future, increased responsibilities and repression of feelings and frustrations to be some of the most significant problems and coping strategies for siblings. Similarly, Gill and Wells

(2000) reported that following an ABI, siblings noticed remarkable change in their injured sibling, experienced a different daily life rhythm, “mixed emotions”, increased task and cognitive-emotional responsibilities, redefined relationships, and an overall change in self. The current framework, however, shows how these previously identified constructs link together, thus enhancing their meaning and explanatory power.

An example of how this framework had enhanced the explanation of previous findings can be found in the literature on parental attention and differential treatment. For instance, McHale and Gamble (1989) found that siblings of children with a range of disabilities displayed dissatisfaction with differential treatment, which tended to lead to anxiety and depression. Similarly, Bischoff and Tingstrom (1991) found that well siblings perceived their sibling with disabilities to receive a greater amount of maternal attention. Although interesting, these quantitative studies fail to provide information about how and why siblings manage this differential treatment, information that is essential for intervention. This study has expanded on the impact of parental differential treatment on siblings in a similar way to another qualitative study conducted by Chesler, Allsweed and Barbarin (1992).

Chesler et al. (1992) reported that siblings of children with cancer experienced jealousy and anger in reaction to the extra attention their ill sibling received, but managed these feelings by repressing them because they understood their siblings’ need for the extra attention. They also reported feeling guilty about their jealousy. These findings are consistent with those presented in the current framework. However, the current framework suggested that siblings may have repressed their feelings to avoid the possible disequilibrium (e.g., family turmoil, vulnerability of ill sibling,

vulnerability of their parents) that would result if those feelings were given voice. The current study also suggests that siblings' feelings of guilt associated with their jealousy could be motivated by the concepts of *sorrow*, *empathy* and *disenfranchised loss and grief*, and that these feelings are unlikely to exist alone, but rather co-exist in a complicated mix of ambivalence.

Thus, the grounded theory framework identified in this study has confirmed many previous findings in the sibling area. However, the coherent framework has also provided a context into which these unrelated constructs could be integrated and linked, potentially increasing their explanatory power.

The Current Model Applied to the Loss and Adjustment Process

Another strength of this theory is that it has confirmed and extended previous research regarding the losses following ABI from the siblings' perspective. It confirmed previous studies regarding the cyclical impact of an ABI on the family (Kendall & Buys, 1998; Kosciulek et al., 1993; Martin, 1990), but provided a sibling's account of the impact. The current model also confirmed and extended the broader literature on siblings of children with an ABI in that it explicated a range of losses that have not previously been identified or made explicit from the sibling perspective. Although studies have documented processes of loss, grief, and adjustment in people impacted by disability, the current study suggests that, following ABI, siblings experience a grief, loss and adjustment process that mirrors that of their injured sibling.

The current study supports and extends the broader literature regarding loss and grief as ongoing aspects of many long-term and life-altering adversities, such as disability (Teel, 1991). Indeed, the current study has highlighted that an ABI results in

a plethora of non-finite losses and associated grief for siblings. The impact of ABI (i.e., cognitive, emotional, behavioral and psychological changes) led siblings to grieve the “loss” of their injured brother or sister who became a *familiar stranger*. In many cases, siblings lost a playmate, confidante, and reciprocal friendship. They also experienced losses within the family unit (i.e. loss of belonging, loss of parental attention). Siblings felt immense sorrow for their injured sibling as well as grief for their own losses. Similar to grief responses highlighted in previous literature (Murray, 2001a), the siblings’ response to the many losses was varied and complex in nature.

For instance, the concept, *emotional turmoil* (see Chapter 5), described the array of ambivalent emotions, such as anxiety, jealousy, annoyance, chronic worry, sorrow, loss and guilt that siblings experienced. Although normal reactions to situations of loss (Bruce & Schultz, 2001; Murray, 2001a), these feelings were complicated by the concept of *disenfranchised grief*, which prohibited siblings’ perception that they had a right to grieve. Bruce and Schultz (2001) suggested that, “with no physical death to mourn, grief is more often than not totally disenfranchised [in that] the people involved in these situations are denied a socially recognized right to grieve... [To avoid appearing] to complain unduly, these ... people disenfranchise their own right to grieve” (p. 13). Thus, the losses that siblings experienced were not only tumultuous, ambivalent and complex, but were unlikely to be addressed as indicted by the strategy of *emotional repression*.

Similar to models of family adjustment to an ABI (Kosciulek et al., 1993; Williams, 1991), the theory presented in this study highlighted that the evolving nature of an ABI ensured that the many environmental and emotional losses siblings experienced were ongoing and that equilibrium was constantly threatened. The model

illustrating the evolution of disequilibrium in this study (see Chapter 5) closely resembles William's (1991) model of episodic loss reaction (p. 85) to describe the impact of an ABI on family. The current findings, however, provide an in-depth understanding of the sibling experience regarding the non-finite nature of ABI and the disequilibrium it represents. Specifically, the losses siblings experienced were triggered by memories, previous schemas about the *world that was*, the tendency for children with an ABI to "grow into their deficits", the inevitable transitions in life (e.g., transitions from primary school to high-school; entry to employment; independent living), and everyday activities presenting elements of risk (i.e., skate-boarding and crossing the road). In this sense, the theoretical framework in the current study also lends support for models depicting the recurrent process of adjustment to losses, such as an ABI (Kendall & Buys, 1998), and proposes that sibling adjustment to an ABI may follow a similar trajectory to that experienced by their injured sibling.

Researchers have clearly documented the inappropriateness of "time-bound" definitions of stage models regarding the adjustment and grief process of individuals with an ABI (Banja, 1992; Kendall, 1998; Wikler, Wasow & Hatfield, 1981). Rather than implying that adjustment to life altering losses reaches a definitive "end point", such as acceptance, reorganization, and reengagement (Murray, 2001a), adjustment to an ABI has been demonstrated to be chronic and recurrent (Davis, 1987). Adjustment to an ABI is "viewed as a gradual process of learning to tolerate an almost intolerable set of circumstances Therefore, [becoming] a continuous life transition rather than a time-limited process where chronic grief is considered pathological" (Kendall & Buys, 1998, p. 17).

Consistent with this theory, the current findings illustrated that siblings were required to continually integrate the on-going losses resulting from their injured brother or sister's ABI through the process of navigating. The findings also proposed that siblings' adjustment to their brother or sister's ABI occurred in an iterative manner, whereby siblings navigated the disequilibrium caused by the losses. Indeed, Murray (2001a) suggested that reactions to loss are fluid and may be altered to allow for each new loss to be integrated. The concept of *navigating* is akin to trial and error responses that describe how siblings continue to integrate the losses into their lives, vacillating between *challenging new rules with old tools*, *trying and buying*, *merging the familiar and unfamiliar* and *integrating*. The concept of navigating thus explicated the processes that siblings used to integrate the ongoing changes in their lives.

In summary, the framework presented in the current study supported many constructs and theories of family adjustment to an ABI identified in previous studies that explored the impact of an ABI, disability and illness on siblings and family members. The framework also provided support for the on-going nature of loss, proposing that non-finite loss results in a complex process of adjustment that requires constant integration and iterative navigation. The similarities proposed between the impact of an ABI discussed in this framework and the losses resulting from other traumatic and adverse life events further support the notion that loss is a universal concept (Murray, 2001a; Trolley, 1993; 1994). Thus, the processes described in the current framework have the potential to contribute to the understanding of the impact of an ABI on family members, and may provide a template for understanding the processes by which losses of a non-finite nature impact on young people over time.

Deepening Knowledge of Family Systems Theory following an ABI

Most researchers exploring the impact of an ABI on family members have used the principles of family systems theory (e.g., Gill & Wells, 2000) to interpret their findings. Family systems theory proposes that a change in one member of the system creates a change for the entire family unit (Maitz & Sachs, 1995). Family systems theory also proposes that family members take measures to restore the family system to a state of homeostasis following disruption (Kay & Cavallo, 1994; Newsome & Kendall, 1996). As would be predicted by family systems theory, this study has highlighted the enormous impact that a child's ABI has on his or her siblings. However, the current study has extended family systems research by suggesting that the concept underlying *change* is that of losing equilibrium. Losing equilibrium, as highlighted above, implies that the conditions that cause disequilibrium are ongoing and not just related to the ABI sequelae, but also to the secondary losses, such as change in the family system. Thus, the study details the nature of the changes that cause the siblings (and perhaps other family members) to change. It also details how they change and suggests that the degree to which siblings perceive equilibrium to be disturbed appears to underpin their motivation to restore equilibrium, or homeostasis, in the family system.

Losing Equilibrium: Constant Change in the Family System

For siblings in this study, the issue that contributed most to disequilibrium was the level of disparity between the *world that was* and the *new world*. Life events that threaten major schemas about *how the world should be* significantly jeopardize an individual's sense of identity, which disrupts their emotional and psychological sense

of balance and control (Bruce & Schultz, 2001). As highlighted in the current grounded theory framework, the evolving and insidious nature of an ABI was a persistent threat to the siblings' life patterns. Factors that impacted on the level of disequilibrium included the enduring vulnerability of their injured sibling, parental absence, parental vulnerability, family turmoil, and siblings' perceived loss of place in their family. These factors continually undermined the siblings' sense of safety, security, predictability and control (see Chapter 5) in the family system. Siblings' basic assumptions about their parents' availability, consistency and support were continually threatened by these factors. This notion supports Murray (2001b) who suggested that "when an assumption central to the child's security is threatened by loss, the whole world becomes less secure" (p. 9).

According to Bruce and Schultz (2001), the future is perceived to be a predictable entity for most people in the Western world. They proposed that the vulnerability and unpredictability of the assumptive world becomes apparent only when it is under threat, and that confronting this vulnerability represents an essential part of the trauma itself, as found in the current study. Thus, the concept of vulnerability appeared to account for the level of disequilibrium experienced by siblings, and that this sense of vulnerability regarding the environment was ongoing.

Bruce and Schultz (2001) suggested that when exposed to the vulnerability of life and mortality, young people find refuge and assurance from their parents to develop feelings of inner certainty. However, the events and conditions surrounding an ABI, as identified in the current study, prevented parents from actualizing this role. The data showed that parents were physically and emotionally absent, were required to prioritize the needs of the child with an ABI, and displayed visible vulnerability,

sending messages to the siblings that their previous pillars of support were crumbling. Facing this personal adversity brought the siblings face-to-face, often for the first time, with the issue of how to regain a feeling of personal safety and equilibrium.

Regaining Equilibrium in the Family Unit

The finding that siblings take responsibility to regain equilibrium is consistent with family systems theory and other models of family adaptation to an ABI (Kosciulek et al., 1993). The current study, however, elucidated the complex process employed by siblings in order to regain equilibrium. This study also suggested that processes generally considered to be dysfunctional (i.e., task, care and emotional responsibility) may be legitimate coping responses that are employed by siblings of children with an ABI.

Murray (2001b) contended that in the face of significant loss, children “make desperate attempts to control elements of their worlds...” (p. 9). Similarly, the current study found that in response to the losses in the family system resulting from an ABI, siblings made many sacrifices in an attempt to restore a sense of equilibrium in the family. They employed an adaptation process that was non-linear, ongoing and fraught with the reminder of unpredictability. To do this, siblings sacrificed many aspects of themselves and their childhood.

In family systems theory, equilibrium or homeostasis in the family unit is restored by challenging the current status of the family hierarchy and relationship boundaries (Whitchurch & Constantine, 1993). According to family systems theory, a hierarchy represents the arrangement of the family system into layers of delegation according to their power and authority (Whitchurch & Constantine, 1993). A parental

sub-system should be more powerful than the sibling sub-system, with the former exercising parental authority over the latter. Within the sibling sub-system, older siblings may have more power and authority over younger siblings.

The current findings suggest that siblings actively challenged the natural hierarchy, particularly in the sibling sub-systems, with younger siblings assuming the “older” sibling role. Siblings in the current study even transcended the boundaries of the sibling sub-system and entered the parent sub-system. This study suggests that redefining the boundaries between the parent sub-system and sibling sub-system was a major strategy used by siblings to restore equilibrium and was often encouraged by parents. The *surrogate parent role*, for example, was a coping strategy that allowed siblings to take control and regain a sense of environmental and emotional equilibrium. This study also suggested that if siblings perceived the boundaries of the parent sub-system to be impermeable, they were likely to withdraw to seek equilibrium outside of the family system. This strategy often led to disharmony and family breakdown. Thus, taking responsibility was an important strategy to retain equilibrium in the family unit during this time.

In this sense, the current study confirmed Farber’s (1960) hypothesis of role crossover in siblings of children with congenital disability. Farber (1960) suggested that sibling relationships in which one child has a disability may alter the natural progression of these roles in that role relationships become less symmetrical over the years as younger siblings “catch-up” and eventually surpass their older sibling’s cognitive functioning. Farber (1960) proposed that this period of cognitive crossover would be accompanied by a crossover in sibling roles, in that the younger child would assume role dominance and status/power over their older disabled sibling. Although

the role patterns between children with congenital disability and their siblings differed to those of the control group in Farber's study, there has been no evidence in the literature to suggest that role cross-over is harmful to the individual sibling or their relationship (Stoneman, 2001). In light of family systems theory, however, the findings of the current study suggest that the impact on siblings and the sibling relationship following an ABI may be profound as this role change is likely to be sudden, causing a high level of disequilibrium, not only for siblings, but for the sibling relationship. Further, the findings of the current study have shown that much of this role change may be related to the increased responsibility that siblings feel for their brother or sister, as illustrated in the concept, *surrogate parent*.

Indeed, the current study has suggested that the concept of responsibility may be more complex than previously thought and may, in fact, be an important coping mechanism that siblings used to regain emotional and environmental equilibrium. Siblings assumed responsibility to enhance their sense of control over the perceived unpredictability of their circumstances. The study also identified a sense of emotional responsibility and sacrificing behaviors employed by siblings, such as repressing their expression of emotion for the well being of their family.

In a few studies, a link has been made between emotional consequences and taking responsibility. For instance, self-reports of siblings of children with disabilities and chronic illnesses have indicated that the process of taking responsibility for the future care and well being of their brother or sister may manifest as worry (Crnic & Leconte, 1986; McCullough, 1981; Seligman & Darling, 1997). In interpreting these findings, Damiani (1999) suggested that worry, and not the responsibility itself, is a precursor of anxiety and depression in siblings. The current study, however, has

suggested that siblings' worry for the well being of their injured brother or sister motivates them to take responsibility, and that this is a functional coping process that assists them to regain equilibrium. For example, siblings believed that if they were *vigilant minders*, and/or sacrificed their *expression of emotion*, that they would be able to minimize their injured sibling from becoming re-injured or minimize additional turmoil for their parents who were perceived to be vulnerable. Studies have often criticized the process of increased responsibility in siblings because of its negative consequences, however, responsibility may in fact be an important coping response that assists siblings to manage their environment and to feel more in control.

Finally, for some siblings in this study, emotional responsibility in the form of self-blame was identified as a possible method of controlling vulnerability in the world. Some researchers have claimed that, in certain situations, self-blame can be adaptive and facilitate well being because behavior is perceived to be controllable and thus enhances feelings of empowerment over the future (Janoff-Bulman, 1979; Janoff-Bulman & Wortman, 1977). However, the majority of findings regarding self-blame for negative life events have indicated that self-blame is maladaptive.

For instance, Healy, Stewart, and Copeland (1993) found that children who blamed themselves for their parents' divorce, reported more internalizing and externalizing symptomatology than children who did not employ self-blame. Similarly, other research has identified self-blame for negative life changes to be associated with lowered self-esteem and life satisfaction (Pruccia, Kinicki, & Braker, 1993), and higher levels of PTSD and depression (Joseph, Brewin, Yule & Williams, 1993). Thus, although responsibility to regain equilibrium may provide siblings with a sense of control over their environmental disequilibrium, it is likely to burden them

emotionally. The current study has shown that self-blame could indeed be motivated by the need to regain control, but is likely to result in long-term internalizing consequences for siblings.

In summary, the current study has provided a new level of understanding regarding the impact of an ABI on the family system. It has provided a greater understanding of the underlying processes regarding change in the family system that was influenced by an ongoing sense of vulnerability. The study has also detailed the processes that siblings used to regain equilibrium, suggesting that siblings shoulder enormous emotional and care-related responsibility that has not been previously identified.

Accounting for Discrepancies in the Literature

Another major strength of the theory developed in the current study is its ability to account for discrepancies found in the literature to date. For example, through the concepts and processes identified in this study, the proposed theory clarifies apparently contradictory findings, such as those concerning the positive and negative impact of an ABI and other disabilities on siblings. In addition, the current theory supports the suggestion that the discrepancies in previous research are likely to be the result of diverse methodologies (Bluebond-Langner, 1996), rather than from failure to control for variables such as, age, gender, injury severity, and family relationship patterns (Cuskelly, 1999; Lobato et al., 1988).

As highlighted in Chapter 1, some studies have reported that the impact of an ABI and other illness and disabilities on siblings is negative and that they are likely to be at risk of psychological, familial and emotional distress (Orsillo et al., 1993;

Williams, 1997). Conversely, other studies have reported that siblings do not appear to be at risk and may even experience many personal benefits from having a brother or sister with special needs (McMahon et al., 2001; Williams, 1997).

Consistent with study findings that siblings were “negatively” impacted by an ABI and other disabilities, the current study found evidence of differential parental treatment and rejection (McHale & Pawletko, 1992; Stoneman, 2001), anxiety, isolation, concern, jealousy, guilt, repression of feelings (Bendor, 1990; Chesler et al., 1992; Willer, et al., 1990), attention seeking, withdrawal (Carpenter & Sahler, 1991), family stress, and family turmoil (Gill & Wells, 2000; Willer et al., 1990). On the other hand, the current study also identified positive constructs similar to those found in previous studies, such as, maturity, independence and tolerance (Barbarin et al., 1995; Chesler et al., 1992). Indeed, the framework proposed in the current study suggested that both “negative” and “positive” effects co-exist and may, in fact, be inter-related.

For instance, siblings in the current study described ongoing feelings of anxiety, jealousy, guilt, and loss of parental attention, constructs often identified as negative outcomes in the literature. Simultaneously, however, siblings also identified themselves to be more responsible, mature, understanding, and tolerant, constructs synonymous with many of the “positive” outcomes identified in previous literature. However, the current framework has clarified this discrepancy by elucidating the process. Specifically, vulnerability and disequilibrium motivated siblings to employ sacrificing strategies (e.g. surrogate parent) to take responsibility for the disequilibrium, which in turn maintained their maturity, tolerance and responsible behavior. This outcome ensured ongoing sacrifices.

These findings highlight the complex interplay of constructs surrounding sibling outcome following an ABI, which may extend to other health conditions. The theory suggests that the presence of “positive” outcomes do not necessarily negate the presence of “negative” psychosocial outcomes in siblings. Nor should the interrelationship of these two constructs (and others) be dismissed. Indeed, the current findings support the assertion by Houtzager and his colleagues’ (1999) that “researchers frequently infer incorrectly from their results that coping was effective because no adaptational problems were found” (Houtzager et al., 1999, p. 311). This finding is also consistent with Kosciulek et al., (1993) who proposed that even when achievement and balance in individual-family and family-community systems appear to have been successful (positive adaptation), maladaptation may still be apparent in terms of the hidden cost of maintaining balance on family members’ health, development, integrity, autonomy and life goals and tasks.

Thus, the current model suggests that a multitude of factors are likely to exist at once and that assessing the impact of disability on isolated constructs of sibling psychological and emotional functioning will likely fail to articulate the underlying processes that account for why and how such phenomena occur. In this sense, the current study confirmed Bluebond-Langner (1996) who argued that approaches based on either positive or negative underlying assumptions are inappropriate for understanding siblings’ response to illness or disability because any responses to a traumatic situation involves complex and interrelated processes (Bluebond-Langner, 1996).

Hence, given the inability of quantitative research to identify the range of complex issues and interrelationships among constructs it is not surprising that

discrepancies in outcome continue to be found in sibling research. Such discrepancies are unlikely to be resolved if predetermined positivistic methods that have perpetuated the incongruity and confusion in the past continue to be employed. Simply assessing *outcome* (negative or positive) in siblings has failed to elucidate the underlying processes essential for understanding their experience. Thus, it is possible that studies seeking positive outcomes will find positive outcomes and vice versa. Even studies that aim to measure both processes are unlikely to be able to explain the complex relationships and issues between constructs that remain hidden in quantitative research (Shmerling, Schattner & Piterman, 1993).

In summary, the current framework suggests that it is the complex nature of siblings' adaptation to events, such as an ABI, that is responsible for the lack of consensus in the findings. The framework highlights that following an ABI (and possibly other health conditions) siblings encounter a complex range of thoughts, feelings and experiences that do not occur in isolation. Although qualitative research has helped to extend this body of knowledge, it is the conceptual and abstract nature of the current grounded theory that can account for variability and clarify the complexity in this area.

Evaluating the Quality of the Theory

The current findings produced a sound theory when evaluated against the appropriate criterion for evaluating grounded theory (see Appendix N) (Glaser, 1978; 1998; Glaser & Strauss, 1967; Strauss & Corbin, 1990; 1998). Consistent with the objective of grounded theory research, which is to create a new theory that is directly tied to the reality of the participants it represents (Glaser, 1978), the current theoretical

framework discovered the underlying processes that motivated siblings' behavior, which was "difficult, if not impossible, to address with traditional approaches to psychological research" (Rennie et al., 1995, p. 156). Indeed, the current study presented an integrated and parsimonious theory that explicated the main issues of concern for siblings and the processes siblings employed to manage their concerns, which had not previously been articulated in the research to date. The quality of the theory is reflected in that it met the evaluative criteria of *fit*, *relevance*, *functionality* (workability) and *modifiability* (Glaser, 1978), essential criteria by which grounded theory research is judged.

Specifically, the theory adhered to the principles of *fit* in that the categories and concepts were generated from the data and clearly represented the data. The concepts and categories were also presented in enough detail to allow crucial ones to be operationalized and verified in future research. The categories and their concepts were also linked and integrated in terms of their causes, consequences, context, contingencies, and conditions (Fagerhaugh, 1995) so that they produced a predictive element to the theory. Second, the theory was considered *relevant* to the experience of the siblings, as indicated by feedback from the participants (see Member Checking, Chapter 4).

Third, the theory was considered *functional* because it was able to explain variation in the data. The more abstract the concepts and categories, and more variation uncovered in a grounded theory, the more likely the propositions apply to a broad range of situations (Strauss & Corbin, 1990). The basic psychosocial process, *regaining equilibrium*, accounted for a large part of the variation in behaviors, whether varying in type or degree. Indeed, siblings employed a range of strategies, such as

those associated with navigating equilibrium, and sacrificing, all differing in type and degree and dependent on different conditions, contingencies and contexts. However all strategies identified aimed at regaining equilibrium and minimizing the vulnerability associated with the conditions arising from an ABI. Thus, given the generation of abstract concepts, which were discovered from a variable sample, the theory's transferability was enhanced. Indeed, concepts and categories in the current theory were able to account for variation across age, gender, injury severity, time since injury, and even sample, as evidenced by the theory's application to adult siblings and siblings of children with congenital disability.

Finally, another strength of the abstract nature of the theory developed in the current study was that it provided enough variability to be *modifiable*, as evidenced by its ability to incorporate a variety of sibling responses to an ABI, even responses that initially seemed contradictory (e.g., withdrawal and surrogate parent). This quality in the current theory further enhanced its capacity to be *modified* to accommodate change.

The current framework also met criteria proposed by Benoliel (1996) to assess the quality of grounded theory studies. In an analysis of 146 grounded theory publications used in the field of nursing, Benoliel (1996) identified several factors that distinguished sound grounded theory research from other research *claiming* to be grounded theory but not actually *applying* grounded theory. One essential criteria of sound grounded theory research was a focus on "social psychological processes of people undergoing major life changes and to a variable extent, on the environmental circumstances influencing the course of events" (Benoliel, 1996, p. 413). Other criteria considered crucial to the development of a sound grounded theory were that of the constant comparison method, theoretical sampling, multiple comparison groups and

theoretical coding. Indeed, these essential criteria were applied in this study, as illustrated in Chapters 3 and 4.

According to Yee (2001) “the theory that is produced is not a ‘proven’ theory, but rather an integrated set of hypotheses, not just based on conjecture” (p. 31). Indeed, the concepts and themes described in the current model were systematically developed and grounded in the data. Further, the theory’s integration was an indication of its validity and the theory presented justified itself (Yee, 2001).

Despite the demonstrated quality of the theory presented in the current study, and its likely application to other illnesses and disabilities, however, it is limited in its generalizability because of its qualitative development. Indeed, the object of this study was to create a new theory that was directly tied to the reality of individuals, not to verify the theory beyond that yielded by saturation (see Chapter 3). Verification has deliberately been left to subsequent research studies with larger data sets.

In summary, the findings of the current study produced a sound theory when evaluated against appropriate criteria for evaluating grounded theory (Benoliel, 1996; Glaser, 1978; 1998; Glaser & Strauss, 1967; Strauss & Corbin, 1998). The current framework provided specific and in-depth knowledge of the experience of siblings of children with an ABI, however, was sufficiently abstract to enable its likely application to other groups (e.g. siblings of children with illness or congenital disability). Finally, this study provided a detailed framework and set of hypotheses from which components of the theory can be tested and verified in future research.

Implications for Future Research and Practice

The findings of this study increase awareness about the impact of a child's ABI on siblings, from the onset of an ABI to many years post-injury. Highlighted in the current framework is the complex interplay of personal and interpersonal processes that are essential for enhancing future research and practice. The implications for future research are now discussed, followed by the implications for practice.

Research

Given the propensity of past research to assess the impact of an ABI (and other disabilities and illnesses) on siblings using predetermined designs and selected outcome measures based on conjecture, many issues crucial to extending knowledge and practice go unaddressed. Indeed, past research has failed to identify the fact that siblings are often witness to their brother or sister's ABI onset and may suffer PTSD as a result. Recent research has started to explore the incidence of PTSD in children with an ABI (Harvey, Brewin, Jones, & Kopelman, 2003; McMillan, Williams, Huw, & Bryant, 2003), but has ignored the likelihood that siblings are also exposed to trauma. Thus, the current study introduces a set of constructs and hypotheses, grounded in the siblings' experience that can be tested and explored.

Further, the conditions that significantly contributed to siblings' sense of vulnerability (e.g., unpredictability and fragility of injured sibling and parental vulnerability) deserve exploration in terms of the relationships between these constructs and emotional disequilibrium (e.g., anxiety). The outcomes for siblings who engaged in the different strategies for regaining equilibrium also deserve further exploration. For example, how do siblings who employ sacrificing behaviors, such as

the *surrogate parent role*, differ to siblings who continue to employ the strategy of *challenging new rules with old tools*? Are some sacrificing strategies considered more effective for coping with a brother or sister with an ABI than others? Are siblings of children with an ABI more responsible than their peers?

Limiting research to the impact of disability on siblings' psychosocial functioning overlooks fundamental aspects of the siblings' experience, particularly since most measures are not sufficiently sensitive to capture the subtle inter-play of processes such as those identified in this study. Indeed, it has been suggested that siblings are unlikely to exhibit evidence of mental illness related to their injured sibling's disability (Lobato et al., 1988). However, this study showed that siblings may still experience profound changes in their life. Researchers and practitioners are in danger of ignoring the support needs of siblings if they fail to understand their experiences and needs, even in the absence of "pathology". Thus, another important implication highlighted in this study is the necessity for future research to develop measures appropriate to the sibling groups that they wish to study.

Indeed, in a review assessing the impact of disability and illness on siblings, Williams (1997) found that in the studies where no differences were identified between siblings and control groups, all but one of the studies used standardized tools. Interestingly, the one study that did not use standardized tools used the interview method with parents instead of siblings. Thus, the importance of utilizing methods that allow the experience of siblings to be captured and grounded is essential for future research.

The current study also provided a framework that accounted for, yet transcended, the influence of such variables as age, gender, and disability severity.

Thus, the framework supports Cuskelly's (1999) observation that dynamic aspects of family functioning (e.g., perception of parental favoritism) may be more relevant mediators and moderators of sibling adjustment for future research than variables such as age, gender and disability. In addition, the findings highlight the importance of contextualizing these dynamic variables and exploring their relationships with the hypotheses derived from understanding the underlying processes in this study.

The current study highlighted the need for qualitative research to ground and identify issues that may otherwise remain hidden in quantitative research (Rivara et al., 1992; Wade et al., 1995). Given the limitations inherent in qualitative studies (e.g., inability to generalize), however, it is equally important that large-scale quantitative studies verify these propositions before reaching definitive conclusions about the processes identified. It was also suggested that future research pay closer attention to dynamic variables and processes grounded in data, rather than predetermining the importance of "superficial" variables (e.g., age, gender) that have been given priority to date.

Practice

Although the current study informs future research regarding siblings of children with an ABI and other special needs, the major contribution of the framework lies in its ability to inform intervention and practice. Given that the variables affecting siblings' responses to an ABI are complex and integrated, it is essential that each situation be assessed individually. However, meeting the needs of child and adolescent siblings following an ABI requires an understanding of their adjustment process.

Understanding this process will allow future practitioners to implement strategies and

techniques useful to the unique needs of the siblings they assist. The framework provides practitioners with an understanding of the complex interplay of factors that may impact on siblings and how they are likely to react, from the onset of an ABI to many years post injury. The framework also reminds future practice that even in the absence of psychological or emotional “dysfunction”, siblings’ experiences and needs deserve attention.

The process of *losing equilibrium* suggests that one focus for future interventions should be to restore an environmental and emotional sense of safety, security, and control. Thus, interventions should include debriefing, information, inclusion, communication and validation. To address trauma following exposure to the ABI onset, it is crucial that siblings are debriefed. Many siblings in this study were not debriefed after witnessing their injured sibling’s accident and had enduring nightmares, flashbacks and guilt about the event. Although some mixed evidence exists, research generally indicates that critical incident stress debriefing significantly reduces the risk of PTSD after such an event (Watts & de L Horne, 1994). Murray et al. (2002) also suggested that because young people are limited by experience, they are more likely to attribute an event, such as an ABI, to something they did wrong, especially if this seems logical. Indeed, some siblings believed that their brother or sister’s ABI was their “punishment” for doing something “wrong” (e.g., hitting brother or failing to wear helmet). Further, although not a condition identified in the current study, siblings may have contributed to the cause of their brother or sister’s ABI (e.g., driving intoxicated). Thus, it is essential that intervention strategies explore siblings’ beliefs, thoughts and feelings about the cause of the incident to effectively address the deleterious consequences associated with such an event.

To minimize siblings' shock, anxiety, and confusion regarding exposure to the ICU and the possible mortality of their brother or sister, it is also essential that siblings are prepared for what they will see in terms of the injury, the equipment, and nature of coma. This is essential given that some siblings prefer to have constant contact with their brother or sister while they are in hospital.

To increase siblings' sense of security and safety in the family unit, it is imperative that they feel included, that communication is encouraged and that their feelings are validated. Kneipp (1996) suggested that educating siblings, particularly younger siblings, about common parental reaction to an ABI may assist them to better understand the loss of parental attention and differential treatment. Kneipp (1996) also suggested that siblings become involved in the rehabilitation and discharge process. Indeed, the current findings indicated that undertaking the surrogate parent role decreased siblings' sense of hopelessness and increased their sense of control. However, the current study also suggested that this role may increase their anxiety. Thus, siblings should be given a choice about the level of their involvement, because a high degree of exposure to these processes and information may increase their sense of vulnerability if not managed well.

Educating and sensitizing parents to the experiences and needs of siblings is also essential. Given the tendency of siblings to repress their feelings, parents should be encouraged to permit and validate the thoughts and emotions of siblings. Indeed, the current findings suggested that siblings expressed their emotions when parents or friends invited them to talk about their concerns. Brett and Davies (1988) found that limited family communication was one of the main factors that caused siblings to appraise an illness as threatening. Communication during the initial stages of the

recovery process is imperative, because initial coping patterns, such as the *code of silence* identified in the current study, appeared to remain dominant throughout the recovery process.

Practitioners and parents also need to remain mindful that siblings tend to deliberately repress their emotions in an attempt to minimize parental vulnerability. An implication of this strategy is that siblings may appear to be coping well even when they are not. They may not seek support when needed. Thus, approaches to provide assistance to siblings may need to be made outside the presence of their parents, and become a standard component of service provision. In cases where siblings are uncomfortable about talking about their concerns, they should be offered strategies that encourage them to express their emotions, such as, journaling, letter writing, or other forms of respite.

To assist siblings to *navigate* disequilibrium, siblings require information about their injured sibling's injury and how it is likely to impact on them physically, behaviorally, emotionally and cognitively. The current framework has suggested that understanding the nature of an ABI as it relates to their brother or sister may aid siblings to more easily develop new strategies for managing their interactions within the sibling sub-system. In addition, teaching siblings behavior management techniques may assist them to cope more effectively with the changes in their injured sibling's behavior. Information and preparation are likely to reduce the unpredictability and disequilibrium that often ensues following discharge and consequent phases of transition. Indeed, Orsillo et al. (1993) found that siblings of children with an ABI perceived themselves to have ineffectual coping and poor problem solving-skills.

Sacrificing strategies were the most common strategies siblings used to regain a sense of safety, predictability and control following an ABI. Although the current findings did not comment on the effectiveness or psychological impact of these strategies on siblings, it appeared that siblings found these strategies useful for minimizing the environmental vulnerability in their family unit, but not always for minimizing their emotional turmoil. The suggestion that increased responsibility in siblings may impact on their psychological adjustment has not been established (Damiani, 1999), however, it is likely that the enormous emotional responsibility siblings employ will have some impact on their well being. Therefore, although it is not clear to what extent sacrificing as a strategy to regain equilibrium is beneficial, it does appear to have some positive elements, such as restoring a sense of belonging and control in the family unit. Degeneffe (2001) suggested that involvement in the rehabilitation process facilitates empowerment among family members of individuals with an ABI. The data in the current study suggested that removing siblings' ability to undertake roles involving responsibility may increase their anxiety more than their actual involvement (see *vigilant minder*).

Thus, health care professionals and parents should be encouraged to respect the siblings' tendency to make sacrifices, but that their behavior be monitored and excessive reliance on this strategy should be prevented given the long-term changes. It is likely that if siblings are encouraged to express and understand their emotions, and receive feedback from health professionals about alternate strategies for coping with a family member's ABI (Kneipp, 1996; Kosciulek, 1994), some of the potentially "unhealthy" sacrificing strategies (e.g., self-blame) may be minimized or reduced in duration.

It is also essential that siblings are encouraged to explore new ways of operating in their evolving and changing world because attempts to restore it to the *way it was* are likely to result in further environmental and emotional turmoil. Future research and practice should aim to identify and document alternative strategies found to facilitate sibling adjustment.

Given that siblings' tendency to sacrifice may be inadvertently encouraged by parents, educating parents about sibling issues may minimize these behaviors. As discussed above, however, it is important that siblings are given a choice about their level of involvement. If siblings choose to be involved parents should be encouraged to acknowledge their efforts. Further, given that siblings sacrifice many aspects of their childhood, this study has indicated that they should be encouraged to access respite and activities outside of the home. Such activities are likely to limit siblings' sense of responsibility and self-sacrificing behaviors. Finally, because the impact of an ABI is often an evolving and enduring process siblings' needs should be followed up, particularly during times of transition for their injured sibling.

Appropriate Media Applied to Practice

Applying many of the suggested strategies above to practice can be considered a challenging task, particularly regarding the unique needs of children and adolescents. Although siblings require information about ABI, it is essential that this information is delivered in an appropriate setting and through age appropriate media. The current study indicated that the initial onset of an ABI resulted in high levels of anxiety in siblings. Such high levels of anxiety may impede siblings' ability to process information when it is presented. Many siblings described not understanding the

words used by the doctors and nurses to describe their injured siblings' predicament. The entire process -- hospitals, trauma, and equipment -- was novel and uncharted territory. Information processing, particularly with information that is novel and/or traumatic is complicated further when it does not fit existing patterns in individual's schemas (Bowlby, 1980; Bruce & Schultz, 2001).

Thus, appropriate media to aid siblings' understanding is essential. Kneipp (1996) suggested that siblings should receive booklets, handbooks, and family guides about the hospital procedures, rehabilitation and general information about ABI. Information about ABI may increase siblings' sense of control regarding the unpredictable and foreign nature of their brother or sister's ABI.

In line with these recommendations, an outcome of this project was the production of a workbook for school-aged siblings of children with an ABI. This workbook details information about ABI, useful questions to ask doctors, common feelings, thoughts and reactions of siblings, and activities to help siblings understand and adjust to their new conditions.

Feedback from siblings during the member checking process (see Chapter 4) confirmed that validating their emotional turmoil is of paramount importance. Many siblings in this study said, "it was good to know that other people feel the same way", when asked if the themes presented in the current framework related to their experience. Indeed, Murray et al., (2002) highlighted the importance of assisting children in situations of loss and grief to understand that their feelings are valid and "normal". A focused attempt was therefore made by the current researcher to organize educational support groups for adolescent siblings of ABI survivors. Although previous research has found these groups to benefit child and pre-adolescent siblings'

(Lobato & Kao, 2002), the interest level for attending such a group in the adolescents contacted was low. These adolescents reported that they were uncomfortable sharing their feelings with strangers. Indeed, the current findings indicated that many siblings felt uncomfortable talking about their thoughts and feelings.

Thus, given the findings that validating and “normalizing” feelings were useful (yet potentially avoided in a group setting), another outcome of this study was the production of a video for adolescent siblings. The video follows the stories of five siblings whose brother or sister sustained an ABI. The thoughts, feelings and processes described in the current framework are illustrated throughout the video. Although not yet evaluated, the video is envisaged to validate siblings’ experiences, regardless of whether or not they choose to talk. As many siblings experience disenfranchised grief, validating their emotions is particularly important as it is likely to give them permission to express themselves. The video also provides an educational tool for parents to understand the experience of siblings. Encouraging parents and siblings to view the video together may assist to open the channels for communication.

Due to the wide reaching implications of an ABI on siblings, it is crucial that schools be informed about the impact of an ABI on family members. Encouraging teachers to offer siblings’ support by lessening their workloads, particularly, when their brother or sister is first injured, is likely to facilitate them through the initial period of change.

Conclusion

Utilizing a grounded theory approach the current study discovered a comprehensive framework of sibling adjustment to pediatric ABI. This framework has not previously been articulated in the literature to date. The framework suggested that siblings experienced an evolving loss of environmental and emotional equilibrium influenced by exposure to unforeseen circumstances, mortality, the enduring vulnerability of their injured brother or sister, and the perceived vulnerability of their family unit. Exposure to these conditions presented many losses for siblings, which threatened their sense of security, safety, predictability and control for many years post injury. The current findings suggested that in response to this loss of equilibrium, siblings employed a variety of strategies, such as navigating, and sacrificing behaviors to regain a sense of equilibrium. Regaining equilibrium ranged from attempts to restore the family unit to previous levels of operating (e.g., challenging new rules with old tools) to strategies assisting to minimize further disequilibrium (e.g. surrogate parent). Given the evolving nature of an ABI, these strategies were constantly modified and evaluated by the siblings in this study.

The grounded theory nature of this framework developed, integrated and contextualized many existing constructs identified in previous research on siblings of children with an ABI. The functional nature of the theory increased its application to siblings of children with other disabilities and children experiencing loss. The framework also accounted for discrepancies in past research and provided a set of hypotheses and propositions, grounded in the data, which can be applied to future studies on siblings. In this regard, the current theory presents a major contribution to the field of sibling research and practice.

This study has clearly demonstrated the crucial need for hospitals, rehabilitation services, health professionals and parents to recognize and acknowledge the experience and needs of siblings. The current model provides an understanding of the siblings' experiences and needs, from which, future intervention strategies can be informed. Specifically, siblings are likely to require debriefing, age-appropriate information, preparation, and education about their brother or sister's ABI. Siblings are also likely to benefit from understanding and support, acknowledgement and validation, permission to express their fears and concerns, and choice about their level of involvement in their injured sibling's recovery process. The current study also highlighted the importance of assessing, addressing, and following-up siblings' individual needs, even in the absence of obvious "pathology". In addition, the findings have resulted in the development of age appropriate and practical media (i.e., a video and workbook for siblings) to assist siblings to cope effectively. Ultimately, however, the current study enabled the experiences of siblings of children with an ABI to be brought out of the shadows.

APPENDIX A

Interview Guide

The Experience of Siblings of Children With Acquired Brain Injury

STAGE 1 - JOINING

- Introduce self to parent and child. Give a brief recap to both about the purpose of coming to the interview (this eliminates any confusion between child and parent and allows the child to see interviewer interact with parent and gain a sense of trust from interviewer (Geldard & Geldard, 1998).
- Outline confidentiality to child in front of the parent. Tell child that if they reveal something that means they are not safe, someone may need to be told, but this will be discussed with the child first.
- Invite child into the interview room without their parent(s).*
- Offer child a cold drink.*
- Thank child for agreeing to be interviewed and explain reasons for interview
- Explain the interview process, child's rights, and the estimated time length of interview. Remind child that the interview will be recorded and gain their verbal agreement to record (signed consent received from parent and child prior to interview).
- Discuss with the child that at anytime if they feel uncomfortable, do not wish to answer certain questions, or wish to withdraw from the study, that they have the right to withdraw. If the child is shy, work out a special sign with the child (i.e. finger on mouth) to indicate they do not wish to talk about the issue.
- Tell the child that you want to ask them some questions about their sibling, but that the interview is mostly interested in finding out about them.
- Start recording the interview.

STAGE 2 - RAPPORT BUILDING

- Ask the child general questions about his/her friends, hobbies, activities, school, future career, etc.
1. What are your main interests?
 2. Do you play any sports?
 3. Do you have any special hobbies?
 4. What grade are you in at school?
 5. What is your favorite subject?
 6. What do you want to do when you leave school?
 7. Do you have to help out around the house? What do you do? What would happen if you don't feel like helping out around the house? How do you feel about that?
 8. What sort of things do you do when you go out, or just hang out?
 9. With whom do you hang out or go out?

Each child will be presented with a sheet of paper displaying facial expressions that depict different moods and feelings. This will be used as a tool to help them identify and label feelings and thoughts of their own.

* Only when interview is conducted at university or hospital.

APPENDIX A Continued

STAGE 3 – INFORMATION GATHERING

KEY: X = substitute X with the name of the sibling with a disability

ACTIVITIES/ QUESTIONS	PURPOSE
1. Genogram and a picture of their circle of friends. Ask child to draw a picture of family first with circles indicating closeness of the relationships (give examples), then ask questions (tell me about....). Repeat for friends.	Gain a sense of the child's perception of his/her family dynamics and friendship group.
<p>2. A) History trip: On this paper I have drawn a time line starting from the year you were born to now. I would like you to write on the time line any events that have been important to you in your life. It can be any event(s). Some events may be happy events and some may be sad events. Some events might involve other people; some might just involve you. Some people have a few, while some people have more. You can write down as many or as little as you like. Break task into year frames.</p> <p>B) Now I would like you to pick for me the 3 happiest events and the 3 saddest events.</p> <p>C) Now I'd like you to rate for me the 3 things you think about most of the time.</p>	<p>A) Gain a sense of whether the child considers their sibling's injury as a significant event in their life. To gain a sense of other significant events that may influence the child's life. What events the children found most significant.</p> <p>B) To gain a sense of how the child evaluated the meaning of the events in terms of making them happy or sad.</p> <p>Gain a sense of whether time since injury and/or age influence perception of significance of event.</p> <p>C) Understand how much the non-disabled sibling thinks about their sibling.</p>
<p>3. Summarize history trip and linking sentence ("Now I would like to ask you some questions about you and your family. Is that okay?")</p> <p>The following section aimed to explore the experience of siblings. Topics included: the perceived impact of their brother or sister's ABI on various areas of their life; and how they coped with the ABI.</p>	Acknowledge what the child has spoken about, and allow a neat transition to next questions considering the diversity of previous answers.

APPENDIX A Continued

<p>“How has ABI impacted on different areas of your life?”</p> <p>Prompts: On this paper I have drawn all different areas of your life (parents, school, friends, activities, feelings, thoughts, sibling relationship, other).</p> <p>“Tell me about any changes you may have experienced as a result of having a sibling with ABI”</p> <p>“Tell me about any benefits or difficulties you have experienced as a result of having a sibling with ABI.”</p> <p>Further, probe questions were used to explore the siblings’ experience in-depth:</p> <p>“Tell me about an incident when X happened; or what was that like for you?”</p>	<p>Open questions to identify how the child perceives the disability to have affected different areas of their life.</p>
<p>FURTHER EXAMPLES OF PROMPTS:</p> <p>5. Is there anything that you would like to be doing at the moment, but are not?</p>	<p>Gain a sense of what the child wishes to be doing at present.</p>
<p>6. Are you able to do this? If not, what are the reasons you don’t do these things sometimes?</p>	<p>Is the sibling’s disability a factor in the child not being able to do certain activities?</p>
<p>7. Do you like having friends over? Do you like going over to friends’ houses? Which do you prefer? Why?</p>	<p>Gain a sense of whether the child accepts or is embarrassed by their sibling’s disability.</p>
<p>8. How would you describe your relationship with X? (OR) What do you think about having X as a brother? Have you always been like this with each other? Has anything changed?</p>	<p>Gain a sense of the sibling relationship and identify if any losses in the relationship have occurred as a result of the disability. Identify any role reversal.</p>
<p>9. Do you think about X much? When you think about X, what do you usually think?</p>	<p>Does the child think about their sibling much and in what ways.</p>
<p>10. Since X’s injury do you feel that you have changed in any way?</p>	<p>How has having a sibling with a disability changed the child?</p>
<p>11. Tell me about any hard times for you since X’s injury/onset? Why? What happened?</p>	<p>Is the sibling with the disability a source of hard times for the child?</p>
<p>12. Describe what it is like to live in your family?</p>	<p>How the child perceives living in the family.</p>

APPENDIX A Continued

13. How would you describe the relationship between X and your parents? (OR) Describe how X and your parents get along.	Examined in conjunction with question 20, to see if the child believes he/she is treated differently to their sibling (resentment, jealousy).
14. What kinds of things do you do when X is sick (think, feel, do)?	What expectations does the child have of self in helping their sibling?
15. Tell me about a time you felt worried for X. Do you ever feel worried for X? Why do you think that is? What do you do when you are worried for X?	Understand child's feelings and thoughts.
16. Tell me about a time when you felt lonely.	Identifying sources of isolation and loneliness in the child.
17. How would you describe your relationship with your parents? (OR) What is it like to live with your parents?	Follow on from question 14.

In addition to the above, children will be asked the following questions to gain an understanding of how they perceive their sibling's disability.

4. Information: Example Questions	REASON
1. Could you tell me what happened to X? How long ago? Do you remember much around that time? What sort of things can you remember about that time?	Gain an understanding of how much information the child has regarding their sibling's disability. Coping strategies
2. What do you know about X's injury/illness? (Information about the disability - source, time, extent of information, reactions to the diagnosis, satisfaction with the information). [onset, etiology, course, prognosis, visibility, functional implications]	Child's involvement in their sibling's disability. Family information sharing.
3. Who told you about X's injury? Were you happy with this information? Why/why not? Who would you like to have told?	
4. Do you have contact with other families with a child or parent with a disability?	
5. COPING: Example Questions	
1. If your friends' brother or sister got injured or was unwell for a long time, what would you say to them? Would you have any advice for them?	Identify resilience and coping strategies.

APPENDIX A Continued

2.	Is there, or has there been someone or something special that has helped you to cope in hard times? What did they do to help you cope? What do/did you do to cope? What do you do when you feel like-?	Identify social support, resilience and coping.
3.	Are there times when you would like to talk to someone about your thoughts and feelings? Do you? Who do you usually talk to? If not, with whom would you like to talk? What sorts of things do you talk about?	Identify child's preferred source of support and coping.
4.	What have been the best times that you have had with X? Why? What happened? What did you remember thinking about and feeling around this time? What were your thoughts about X around this time?	Positive question. Gain a sense of what personal and situational factors are involved in good times and are associated with positive coping.

STAGE 4 - DEBRIEFING

- Summarize the information from the interview (hard times and positives).
- Ask child how they are feeling.
- What was the interview like for you?
- Ask child how they felt about the interview – what they liked and did not like.
- Would they like to make any further comments?

STAGE 5 - TERMINATION

- Thank child for being involved.
- Give parents a contact number if there are any concerns.

Directly after each interview, the interviewer is required to complete an observation sheet.

APPENDIX B

Facial Expressions Presented to the Siblings to Assist with Identifying feelings

APPENDIX C

Observation Sheet

ID Number: _____ Date: _____

Gender: _____ Age: _____

With whom did the child come to the interview?/Place of interview

Mood and manner

Interaction - interviewer

Interaction – parent/caregiver

Interaction – sibling

Visibility of condition/functional implications:

Other observations

(Home environment, additional interactions, incidents, etc.)

APPENDIX D

Interview Process Following Analysis: Categories and Mini-Theories Presented in Interview Two.

The following Appendix outlines the categories and mini-theories outlined in the second wave of interviews with the child, adolescent and adult siblings of children with ABI. Figure D1 represents the major concepts diagrammatically, as they are described in the mini-theories and categories below.

A while ago we met and you kindly gave your time to talk to me about your experiences of having a sibling with acquired brain injury. In this tape-recorded interview, we talked about the impact this incident had on you, your relationship with your parents, siblings and friends and about some of the difficulties and benefits that are associated with having a brother or sister with ABI.

Since our interview I have collated all the information we spoke about from yourself plus twenty other siblings and have come up with some themes that seemed to capture the experience of young people who have a brother or sister with ABI. The purpose of our discussion today is to check with you about how much you agree with what I have found. Some or all of the experiences may relate to you, while others may not. There are no right or wrong answers, I just want to know how much the following themes do or do not relate to your experiences of having lived with a brother or sister with acquired brain injury. It is important that you are honest and if you feel that something does not quite relate to your experience, you let me know.

I will read to you the main experiences that were mentioned in the interviews. At various points in the story I read, I will ask you to identify anything that *does not* relate to your experience. Some of what I read, you may have experienced at one time or another, and some you may still experience. Even if you don't experience what I read now, I'd still like you to tell me if you have experienced it before. Also, if you would like to add any comments to the story, please feel free to do so.

Is that clear?

Any questions? If you are unsure of anything during the process, feel free to let me know. In the story when I say sibling – think about yourself in those terms, sibling is meant to represent your role in the story.

Lets start.

APPENDIX D Continued

Most siblings interviewed experienced a range of experiences that I will now describe. Firstly:

Witness

Some siblings said that they saw their brother or sister being injured or becoming ill. They said that witnessing their brother or sister sustain their injury or illness was a frightening and confusing experience, often made worse by seeing their parents upset and scared. They were very frightened by what they saw and many believed that their brother or sister was dead. Many siblings in this situation described that they constantly thought about the event, (such as seeing their brother or sister being hit) had nightmares and flashbacks that they still had several years after their brother or sister had their injury. Many siblings said that they did not talk to anyone about their experience, thoughts or feelings.

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

Self-blame

Some siblings also blamed themselves for their brother or sister sustaining ABI, despite it NOT being their fault, because they thought that their behavior had in some way caused, or failed to prevent, the incident from occurring. Even when there was no way that it was their fault, some siblings still blamed themselves several years following their brother or sisters ABI. Some siblings said that they thought that if only they had done one thing different the injury would not have occurred, especially those siblings who were nearby when their brother or sister was injured. In some cases, the siblings thought their brother or sister with ABI also blamed them for the incident. Again, most siblings interviewed said that they did not talk to anyone about their beliefs that they were responsible, or their fears and thoughts about the event.

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

ICU

Some siblings said that seeing their brother or sister in intensive care and in hospital was a very difficult and traumatic experience and that they were frightened, confused, upset and overwhelmed by what they saw. Much of the trauma and confusion they felt was from their lack of understanding regarding the medical equipment used to help their sibling get better as well as seeing their brother or sister look so sick. They were also scared and upset because they believed that their brother or sister might die.

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

APPENDIX D Continued

Changes

Siblings also said they had to adjust to many physical, and/or emotional and behavioral changes in their brother or sister with ABI. Often siblings described their brother or sister with ABI as unpredictable in that you were not always sure what they would do next, and that they were sometimes inflexible, grumpy and short-tempered as a result of their ABI. At times their behavior was life threatening, stressful and confusing for siblings. Siblings said they became wary of their injured sibling as well as cautious and scared. In addition, siblings also perceived their brother or sister as physically and emotionally fragile in that they believed that they were vulnerable to serious re-injury or even death.

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

Loss

In addition to this, siblings expressed a deep sense of loss as a result of the changes in their sibling with ABI. Siblings said that they felt grief/sadness for the loss of interaction (playing), personality, advice and relationship they missed from their brother or sister. They also grieved/felt sad for the person they “lost” and the person they could have been. The loss siblings felt was described as constant and enduring/everlasting. Some siblings even hoped that their brother or sister would recover from the ABI and return to be the person that they used to be.

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

Now, the next few themes highlight a series of processes that may relate to you. I am going to read out five short stories, much like the ones I have already read, and I’d like you to once again tell me if these do not relate to your experience.

Mini-Process 1

Siblings said that seeing their b/s with ABI in hospital and being in a vulnerable/touch and go life/death situation, and knowing that they may die or be severely disabled was a traumatic and confusing. As a result, the siblings said they felt very anxious and emotionally all over the place. This emotional turmoil and anxiety led to/resulted in siblings not being able to concentrate at school or in activities and their focus and time was given exclusively to their sick brother or sister, in that they would visit their brother or sister in hospital and/ or think about them all the time. This often interrupted their routine and changed their life plans. In some cases this interruption had lasting consequences for the siblings involved, such as they took less risks and had a much greater appreciation for life.

APPENDIX D Continued

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

Anything to add? Other reasons?

Mini-Process 2

During hospitalization of the ill child many parents stayed at the hospital and had very little time and energy for the siblings. As a result of this loss of attention, time and resources, many siblings looked after themselves, household chores and other non-injured siblings. Siblings said that this process continued after their brother or sister came out of hospital in that they were treated differently to their brother or sister with ABI by their parents. They were treated differently in terms of the concessions parents made, and the priorities they gave to the child with ABI because they were sick. Siblings' common reaction to this different treatment was to feel angry, left out and jealous. But, siblings mostly kept these feelings to themselves and felt guilty for feeling this way. In fact, siblings mostly were very understanding of their parents need to sometimes give more time to the child with ABI and they had a feeling that their brother or sister deserved and needed the extra time and resources and attention.

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

Anything to add? Other reasons?

Mini-Process 3

Many siblings saw their parents' sorrow/sadness when their brother or sister sustained their injury. This sorrow/sadness was confronting to siblings who witnessed their parents in a state of confusion, turmoil and loss of control. Siblings believed that they could not anchor themselves to their parents for support because they needed support themselves. Some siblings were told by relatives and friends to be strong for their parents and therefore had such an expectation of themselves. As a result, siblings bottled up their concerns, especially from their parents so as not to further burden or upset them. In fact, often siblings consciously hid their emotions and feelings and made themselves look strong for their parents and shouldered/ took on the responsibility for helping their family feel better. The research interview for this study was the first time some siblings had spoken about their experience, even after several years.

Now, is there anything in the story so far that does not, or never has related to you?

APPENDIX D Continued

Do you still sometimes experience this?

Anything to add? Other reasons?

Mini-Process 4

The changes in the child with ABI, such as their unpredictability and fragility, led many siblings to feel constantly worried about their b/s with ABI. Siblings described thinking constantly about their brother or sister's safety, worried about their health outcomes and their future. They also felt concerned when their brother or sister with ABI displayed unusual behaviors as they wondered what this meant for their health. As a result of the changes in their injured sibling's behavior and consequent vulnerability to recurring injury or death, siblings constantly worried for their injured sibling and became protective of their brother or sister with ABI. Their protective role included keeping a watchful eye on their injured sibling, monitoring their activities, helping them with rehabilitation, protecting them from danger in public or from bullies in the schoolyard. Siblings also noticed that their brother or sister was more dependent on them in that they looked after them and took them out with friends. As a result of all these changes, siblings played a different role with their brother or sister with ABI. Siblings, especially those who were younger than their injured brother or sister noticed that they had become the "older sibling", and in some cases a surrogate parent. Siblings mostly took this role on themselves, although sometimes their parents encouraged it.

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

Anything to add? Other reasons?

Mini-Process 5

Siblings expressed a deep sense of sorrow/felt very sorry for their brother or sister after their ABI and resulting disabilities and illness. They were sorrowful/sorry that their brother or sister with ABI had to continually take medicine, and that they lost lots of friends, job, and activities, to name a few. Siblings expressed feelings of guilt because their brother or sister couldn't do some things anymore that they themselves still could. Siblings also said that as a result of the changes they became frustrated, stressed, angry, and embarrassed about their injured sibling. At the same time, though siblings said that they felt guilty for feeling embarrassed or angry because of a loyalty to not feel as such and also because they knew that their brother or sister could not help it. So, in response, even though they felt angry or jealous, siblings said that they repressed their feelings and just accepted and put up with the way things were as well as withdrew from the situation. They also repressed their feelings and did not physically fight back as much because they did not want to further hurt their brother or sister.

APPENDIX D Continued

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

Anything to add? Other reasons?

Sacrifice

At the center of this whole experience, it seemed that siblings sacrificed or gave up a lot of their own desires and needs. They repressed/controlled/crushed their feelings and did nice things for their brother or sister that they would not have done before their injury. Siblings saw their own needs to be less important than the needs of their brother or sister with ABI. They would happily take the blame for their brother or sister, hid their emotions and ungrudgingly accepted that their brother or sister with ABI needed their parents' resources, attention and time. They were also very accepting of the new responsibilities they had, even if they didn't always like them.

Do you still sometimes experience this?

Anything to add? Other reasons?

Siblings also said that they experienced many personal changes as a result of having a brother or sister with ABI. They said that they had an increased understanding of disability and were more tolerant of differences between people. They also said that they were more patient as a result of having to be more patient with their sibling with ABI. They also described themselves as more responsible and mature.

Now, is there anything in the story so far that does not, or never has related to you?

Do you still sometimes experience this?

Anything to add? Other reasons?

* Compared to your friends, do you think you are more patient, tolerant and mature, as well as understanding of disability?

To conclude, siblings may experience a range of changes, turmoil and upheaval in their family as a result of their brother or sister sustaining ABI, especially when their brother or sister is first injured. Siblings mostly accept and get used to the changes as time goes on and many say that things get easier with time and things just become a way of life. However, siblings indicated that in the process of adapting to the changes, they sacrificed many things for the well being of their family, and to assist with things getting back to "normal" as much as possible. Even many years after, siblings continued to sacrifice certain aspects of their lives.

APPENDIX D Continued

Siblings also indicated that they did not mind taking on this responsibility, which in many cases they placed on themselves. The sacrifices made by siblings included:

- bottling up their feelings
- giving lots of time and energy to their brother or sister
- being understanding of the extra attention their sibling received
- protecting their brother or sister as much as they could
- biting their tongue and holding back to prevent conflict

Siblings undertook these sacrifices even when they were angry or frustrated even though they knew that their sibling was unable to help it.

Many times what appeared to maintain the siblings' responsibility was their worry or concern for their brother or sister (due to their fragility or unpredictability); sorrow for their parents because of the hard time they had been through; seeing their brother or sister so close to death; sorrow for their sibling and their losses; and at times guilt for being the well sibling.

How much can you relate to this? Does it make sense to your experience?

Any comments or questions?

Thank you for your time.

APPENDIX D Continued

Figure D.1. Sacrifice For The Well-Being Of The Family: The Process Of Managing The Change And Turmoil

APPENDIX E

Interview with Physician: ICU

The following questions relate to children who have sustained acquired brain injury (ABI) from trauma (MVA, pedestrian); infectious diseases (meningitis, encephalitis), tumors, or lack of oxygen to the brain (near drowning, choking, stroke) and who are admitted to ICU.

1. Description of the process children and their families go through from the time they enter ICU to the time they leave. Is there a standard process?
2. Is there any formal or informal guidelines or briefing for families and siblings, when children are first admitted or before they see the child, to ICU about what is involved and what to expect (in terms of what they will see, outcomes, etc.). What does this involve? Who is involved in this informing process?
3. Is there formal or informal debriefing for families/siblings who have a child in ICU. Do families often utilize this?
4. If a child has severe ABI and you do not expect them to live or at best if they do live you expect that they will be severely intellectually and or physically impaired, who, what and how is the information given to families?
5. At what stage, if at all, are families given the opportunity to participate in the decision to allow the child to continue on life support or not?
6. In your observation, do siblings of the child in ICU visit? How often? Ages? Is there an age limit?
7. Have you noticed reluctance by parents to involve the siblings in the ICU process?
8. Is there special childcare services provided by the hospital for siblings whose brother or sister is in ICU?
9. In your observation, do friends of the child in ICU visit? How often? Ages? Is there an age limit?
10. Who most often stays with the child? Where do they sleep? For what period of time are they allowed to be here with the child?
11. Have you observed the reactions of siblings of children in ICU as a result of ABI? What have been your observations?

APPENDIX E Continued

12. Although all ABI is different, what is the average length of stay in ICU for a child with severe ABI?
13. In your observation, do most families have the perception that once the child's eyes open they will be all right? Is this myth dispelled? Does it seem to make a difference?
14. Given your experience in ICU, what do you feel would be the ideal process for families and siblings of children with ABI who are admitted to ICU? What would you like to see happen?

APPENDIX F

ID NO: **Centre for Strategic Human Services, Griffith University**
Ms. Samantha Bursnall, Dr. Elizabeth Kendall and Dr. Nicholas Buys

Parent Consent Form

This form tells you about a Research Project we are conducting at Griffith University. By signing at the bottom of this form, you can indicate that you have read the details and have agreed that you and your child are willing to participate in this new project.

Project Aims

The project aims to understand the experiences of children who have a sibling with ABI and what is likely to assist these children to cope. We envisage that this research will contribute to the assistance available to children and their families in similar situations.

If you and your child agree to be involved in the research, we would like to interview you and your child by means of written questionnaires and a brief audiotaped interview. These questions should take about **one-hour** and could be conducted in your home, at our university or at any other place you nominate. The topic of these questions will be your perception of your non-disabled child's functioning and the help, if any, you believe would benefit children such as yours and those in similar situations

The questions we will ask your child will revolve around finding out what they think and feel about having a sibling with special needs, what opportunities and benefits does having a sibling with special needs present for them, what factors sometimes make having a sibling with special needs difficult, and what factors have helped them to cope. The questionnaires will ask them questions about their family and relationships, as well as about what they think and feel. We acknowledge that the nature of the questions may be considered sensitive and, therefore, only trained child researchers will be interviewing your child. If at anytime during the interview our researcher believes that your child appears upset, the interview will be stopped immediately. Further, if your child, for whatever reason, simply does not wish to participate or continue talking to our researcher, their decision to withdraw from the interview at anytime will be respected.

This project presents you and your child with an opportunity to share your unique experiences with our research team who are very much looking forward to meeting and talking to you. If you have any questions or would like more information about the study, you are welcome to contact us on the number provided below and we will be happy to talk to you.

Please read the following and indicate your decision by returning the section below.

- **This project does not involve risks or costs to my children or myself.**
- **My participation and my child's participation is voluntary. I understand that it is my right and my child's right to withdraw consent at anytime during the project.**
- **Any information my child or I provides will remain confidential and our names, or any identifying information, will not appear on that information.**
- **My name and contact details will remain confidential and will not be used for any further research.**
- **Any information I supply will not be given to my child or any other party, and any information my child or teacher provides will remain confidential from me or any other party.**
- **I will receive feedback about the findings of the study and can contact the researcher, Samantha Bursnall, at anytime on 3382 1206**

ID NO:

NAME (need not be full name): Contact Telephone Number:

.....
 Contact Address (optional):

.....
 Please tick one:

☐ I AGREE TO PARTICIPATE IN THE STUDY.

☐ I HAVE DISCUSSED THIS PROJECT WITH MY CHILD,.....WHO
 HAS ALSO AGREED TO PARTICIPATE. I AUTHORISE YOU TO INTERVIEW HIM/HER.

☐ I AUTHORISE YOU TO INTERVIEW MY CHILD'S TEACHER.

Signed:

Date:/...../.....

APPENDIX G

Child Consent Form

Hello there.

My name is Samantha and I am a researcher at Griffith University. I am really interested in talking to young people, such as yourself, about what it is like to have a brother or sister with special needs. But, mostly I would like to find out a bit about you, such as what sorts of things you like to do and what things you think about sometimes.

If you would like to talk to me, I may want to audiotape our conversation, if that is okay with you. The best thing about this conversation is that you can say as much or as little as you like. I may also ask you to fill out a questionnaire, which has no right or wrong answers.

Anything you tell me will be kept private from everyone (unless you tell me something that means you are not safe) and you will be identified with a special number instead of your name. Also, if at anytime during the research you decide that you do not want to be a part of the study, that is okay. You have a right to withdraw anytime you like and we will respect that decision.

If you would like to help me, please sign your name at the bottom of this page and return this slip with your parents' form and signature in the envelope provided. When I receive your permission, I will contact you and we can arrange a time and place to meet. If you have any questions or would like to talk to me before deciding please call me on (07) 3382 1206.

I look forward to hearing from you.

ID No.: Name (need not be full name):

Contact Address:

Telephone Number:

Please tick: [] I AGREE TO PARTICIPATE IN THIS STUDY

Signed: (Participant) Date:

APPENDIX H

Adult Sibling Consent Form

ID NO: **Centre for Strategic Human Services, Griffith University**
Ms. Samantha Bursnall, Dr. Elizabeth Kendall and Dr. Nicholas Buys

Consent Form

This form tells you about a Research Project we are conducting at Griffith University with funding from the Financial Markets Foundation for Children. By signing at the bottom of this form, you can indicate that you have read the details and have agreed to participate in this new project.

Project Aims

The project aims to understand the experiences of people who have a sibling with special needs and what is likely to assist them to cope. We envisage that this research will contribute to the assistance available to young people and their families in similar situations.

If you agree to be involved in the research, we would like to interview you by means of a brief written questionnaire and/or an audiotaped interview. These questions should take about 1 hour and could be conducted in your home, at our university or at any other place you nominate.

The questions we will ask you will revolve around finding out what you think and feel about having a sibling with special needs, what opportunities and benefits does having a sibling with special needs present, what factors sometimes make having a sibling with special needs difficult, what factors have helped you to cope and what help, if any, you believe would benefit young people in similar situations. We acknowledge that the nature of the questions may be considered sensitive and, therefore, only a trained researcher will interview you.

This project presents you with an opportunity to share your unique experiences. If you have any questions or would like more information about the study, you are welcome to contact us on the number provided below and we will be happy to talk to you.

Please read the following and indicate your decision by returning the section below.

- **This project does not involve risks or costs to myself.**
- **My participation is voluntary. I understand that it is my right to withdraw consent at anytime during the project.**
- **Any information I provide will remain confidential and my name, or any identifying information, will not appear on that information.**
- **My name and contact details will remain confidential and will not be used for any further research.**
- **Any information I supply will not be given to any other party.**
- **I will receive feedback about the findings of the study and can contact the researcher, Samantha Bursnall, at anytime on 3382 1206**

 ID NO:

NAME (need not be full name): **Contact Telephone**
 Number:

Contact Address

(optional):

Please tick: [] **I AGREE TO PARTICIPATE IN THE STUDY.**

Signed: Date:/...../.....

APPENDIX I

The Grounded Theory Approach

Understanding the grounded theory method is extremely difficult, and as a result, there are many divergent interpretations of its application (Eaves, 2001, Glaser, 1998; Yee, 2001). In fact, many published grounded theory studies have been criticized for failing to adhere to the underlying principles of the grounded theory method (Eaves, 2001). A lack of mentorship by grounded theory originators and their students, the complexity of the grounded theory method (Eaves, 2001; May, 1996; Yee, 2001), and confusion between the divergent interpretations of the method (e.g. Glaser vs Strauss & Corbin) have been blamed for these limitations.

Indeed, most confusion about the grounded theory method results from the divergent methods of grounded theory proposed by two of grounded theory's founders. Grounded theory was discovered by Glaser & Strauss (1967), however, both authors have since developed two divergent models of the grounded theory method, causing much confusion in the grounded theory field. For an understanding of how the methods differ refer to Glaser (1992). In the initial stages of data collection and analysis (e.g. open coding), this study espoused to the principles of grounded theory as outlined by Glaser and Strauss (1967), Glaser (1978; 1998), and Strauss and Corbin (1998). As data collection and analysis proceeded, however, and the researcher's understanding of the method grew, the difference between these methods became increasingly apparent (see Kendall, 1999; Glaser, 1992). What also became apparent was that Glaser's (1978; 1992; 1998) approach more accurately represented the original aims of this study. However, this study utilized some of the techniques outlined by Strauss & Corbin (1998) due to its clarity in application. Although Strauss

APPENDIX I Continued

and Corbin's (1990; 1998) techniques were more strategic and simpler to understand, they resulted in conceptual description more than conceptualization and theory, which were part of the study's aims. Thus, initial processes applied to this study resulted in more conceptual description, than a parsimonious theory proposed by Glaser (1978). Once this realization became clear in the later stages of analysis, the data was subjected to additional waves of analysis utilizing strategies proposed by Glaser (1978; 1998), such as theoretical coding (Glaser, 1978) and more conceptual memoing. Importantly, at all stages of the analysis, constant comparison was adhered to and clues about the emerging theory were taken from the data and remained grounded. Forcing the data was avoided by the utilization of the constant comparison method. Thus, the result of this dissertation is an integrated conceptual theory, based on the methodological principles of grounded theory as espoused by Glaser & Strauss, (1967) and elaborated by Glaser (1978, 1998), and Strauss and Corbin (1990; 1998).

According to many grounded theory researchers, this situation is common among novices to the grounded theory method (Glaser, 1998; Yee, 2001). Nonetheless this study produced a sound theory when evaluated against appropriate criteria for evaluating grounded theory (Glaser and Strauss, 1967; Glaser, 1978; 1998; Strauss & Corbin, 1990; 1998). This criterion is outlined in Appendix O The methods for ensuring this criterion are outlined in Chapters 3 and 4.

APPENDIX J

Constant Comparison

Constant comparison is the core process that assists in developing theory from data. Constant comparison is carried out to assist 1) the development of categories from data, 2) integrating and relating categories and their properties, 3) delimiting the theory, and 4) writing the theory (Glaser & Strauss, 1967). In the initial stages of analysis constant comparison involved the comparison of incidents in the data to each other, which is illustrated by the concept indicator model.

The concept-indicator model (see figure J.1.) directed the conceptual coding of indicators or units of data. This model provided the essential link between units of data and concepts that result in a theory generated from data. The concept-indicator model involved constantly comparing units of data to one another. When an underlying meaning between the units of data became apparent, a conceptual code was applied to the units. When concepts were generated, units of data were then compared to the emerging concepts and were added to the concepts if found to be similar in meaning, thus becoming another indicator of that concept. Comparing units of data facilitated analysis to confront similarities, differences and degrees of consistency of meaning between the data units. Thus, the purpose was to identify the underlying uniformity and its varying conditions which become the generated concepts and hypotheses (Glaser, 1978). The emphasis was on the *meaning* of indicators and the analysis of the meaning, not simply the grouping of like indicators. The aim was conceptual specification, not conceptual definition (Glaser, 1978). The comparison of concepts to further incidents resulted in theoretical

APPENDIX J Continued

elaboration, saturation and verification of the concepts. It also elaborated the density of the concepts by developing their properties and the further generation of concepts (Glaser, 1978).

Figure J.1. Diagrammatic depiction of the concept-indicator model (Punch, 1998).

Finally, while the above comparisons continued throughout the study, concepts were also compared to each other. Concepts that had similar meanings were then compared, based on the constant comparative method, and grouped into categories (see figure 4.2). Coding and categorizing the data decreased the number of units in the data and increased the analytic power of the data (Strauss & Corbin, 1998).

Figure J.2. Diagrammatic depiction of similar concepts and their indicators grouped into categories.

APPENDIX J Continued

The constant comparative method continued throughout the study and eventually categories were compared to categories, and memos to new incidents and memos to memos. Comparative analysis continued into the write up stage. Every new hypothesis was compared against the data to ensure that it was grounded. “In grounded theory interpretations are all rigorously induced from the data, if the full process of constant comparison is followed” (Glaser, 1998, p. 12).

APPENDIX K

Memoing

Memoing is an integral part of grounded theory analysis that was essential for the development of propositions in this study. Memoing involved the informal recording of ideas and theorizing about codes and their relationships (Miles & Hubermann, 1994; Glaser, 1978). Memos included sentences, paragraphs, diagrams, models, short stories or pages that captured the researcher's ideas about patterns in the data, abstract concepts, elaboration of concepts, and the relationship of concepts to each other and to higher-order categories. Memos also include notes about the methodological decisions, and the researcher's biases and reactions to the data. Memos, rather than simply describing the data, should have conceptual content because they assist in moving the analysis from the empirical to the conceptual level (Glaser, 1978). That is, coding involved the systematic part of the analysis; memoing was the creative part (Glaser, 1992). This creative part (memos), however, required verification and therefore, became data that was applied to the processes of theoretical sampling, and constant comparative analysis. In practice, memoing interrupts coding to ensure that ideas are not lost, and should commence from the onset of the study.

Although memos were written about the data from the onset, the memos written in the initial stages of this research tended to be scant and descriptive in nature, rather than conceptual, and focused on people rather than processes. According to Glaser (1978; 1998) conceptualization is difficult, and like the grounded theory method itself is learned through application and practice. As a result, the conceptual development of abstract categories grew towards the end of the analysis. This is a common mistake in grounded theory studies and is often

APPENDIX K Continued

responsible for a resultant descriptive study (conceptual description) rather than a parsimonious, integrated, conceptual theory (Glaser, 1998). Given the potential clinical application of this study, however, description was still important for an in-depth understanding of what ABI is like for siblings, which ultimately assists with making clinical recommendations for future research and practice (Kendall, 1999). Description was important for understanding the experience of siblings of which very little is known. However, to meet the needs of developing a parsimonious theory with predictive power, further conceptualization of the categories was employed.

Although memoing was applied to the data throughout the study, the majority of conceptual memoing was undertaken only after an initial attempt to write about the categories revealed their need for further conceptualization – they were too descriptive. This resulted from the initial descriptive memoing of ideas and a lack of familiarity with the method. Thus, the emerging categories and their properties were subjected to recursive analysis, theoretical coding, comparison, conceptualization, analysis, integration, and continuous memoing. A great amount of care was taken to ensure that ideas were not forced onto the data and that anything new was verified by the data.

Diagrams depicting the links among categories assisted in raising the conceptual levels of the concepts and categories, and made up a large part of the memos. Conceptual memos continued until the write up of the theory was complete. Memos were continually compared to data units, concepts, and categories. Memos were continually subjected to verification by looking for

APPENDIX K Continued

the referent in the data. The final write up of this study evolved over approximately twelve months and resulted in several exercise books filled with memos, diagrams and data resulting in the theory. Appendix M illustrates an example of the development of memos, specifically regarding the development of the basic psychosocial (BPS) process.

APPENDIX L

Examples of the First-Level Conceptualizations Identified Through Open Coding *

Code/Concept (and context)	N**	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Acceptance	11	Reference to the acceptance of the situation and changes resulting from their sibling's ABI and the impact on them.	<ul style="list-style-type: none"> “...I got used to it, I accepted it” (10:16). “That is who he is now, and accept it and work with it and not against it. (06:28)***.
Acknowledgement	3	Reference to acknowledgement for the losses and hard work to be of benefit in allowing sibling to keep going with household chores, etc.	<ul style="list-style-type: none"> “[When my brother was in hospital] my mom used to come home and tell me I was doing a great job and everything, so that was good because it sort of just gave me that boost.” (07:12).
Anger/ attribution	15	Anger directed toward self, parents, sibling for the situation, and or driver/ doctor (perceived to be the “cause” of the accident).	<ul style="list-style-type: none"> “...I was pretty pissed off at the world...” (12:8). “[I was] very upset and peeved off at the driver...” (20:7). “Sometimes I get really angry and sad, stuff like that” (24:20).
Annoyance	16	Sibling description of their brother or sister with ABI as more frequently annoying, frustrating, or irritating since ABI onset.	<ul style="list-style-type: none"> “Sometimes she gets annoying to me...” (03:12). “She used to be really sarcastic, but now [she's] just annoying” (10:20). “He's always walking up the stairs slow and I want him to go faster... and he always talks slow (04:10).
Appreciation for life of injured sibling/ family	14	Reference to realizing the value of the child with ABI as well as of family. (Linked to the realization of fragility of life and the vulnerability and mortality of people and self).	<ul style="list-style-type: none"> “Just the fact that she is alive is important” (22:17). “What has happened to Costa has made me like love him more than I did - Like, see how more important he is now” (17:15).
Bottle-up	23	Holding in and repressing expression of emotions, frustrations, sadness, etc., especially those relating to the ABI and its consequences.	<ul style="list-style-type: none"> “This is the first time I have spoken about it (seven years post injury)” (24:33). “When I'm upset I ...keep it to myself” (11:11).
Change in injured sibling (ICU + long-term changes)	31	General reference to the physical, behavioral, personality, and/ or cognitive changes observed in their sibling, including PTA.	<ul style="list-style-type: none"> “She just changed totally” (03:3). “My brother ... he's had a total like different personality change” (06:10).
Change in relationship with injured sibling	57	Reference to being closer or more distant to child with ABI since the ABI. General changes.	<ul style="list-style-type: none"> “...I don't hang out with him no more” (11:8). “It brought me a lot closer to him” (17:20).

* It should be noted that these conceptualisations and their contexts were altered, extended and elaborated in further analysis. Consistent with the principles of grounded theory (Glaser, 1978), only concepts that related to the final theory were included.

**N = Number of times the code appeared within and across interviews.

*** Codes in parentheses represent the siblings' identification number and page number of the quote found in the original transcript.

APPENDIX L Continued

Code/Concept (and context)	N	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Changed roles	5	Observation that siblings perceive themselves to be more grown up and responsible than the child with ABI, especially the siblings who are chronologically younger.	<ul style="list-style-type: none"> • “Like I am the big brother now, I don’t let him know that...” (06:37). • “I don’t look up to him as a big brother...I look after him more than he looks after me” (23:11).
Confusion (ICU)	58	Reference to being confused by the pace of events, the foreign environment, and the state of the child with ABI. Unclear about the diagnosis, prognosis of the child with ABI. From ICU onwards. Reference to not having enough information about ABI and medical equipment.	<ul style="list-style-type: none"> • “I was the first one to see her...she had her eyes open and then I couldn’t understand why she couldn’t talk, she wouldn’t talk for a few days. And that was pretty hard. No one explained that” (03:20). • “...I didn’t really know what was going on at the beginning” (13:38). • “...I didn’t know what was happening.” (11ms:6-7). • “[I want to know] if he is ever going to get better or not” (24:23).
Constant worry for child with ABI	34	Reference to constantly thinking and worrying about their brother or sister with ABI in terms of their health outcomes and at risk behaviors. Concerning intrusive thoughts.	<ul style="list-style-type: none"> • “I think about him being safe...I think about him a lot for his well-being and how he is doing” (18:31-32). • “I worry about if he is ever going to get off all the tablets he takes” (24:22).
Counselor	1	Consultation of sibling with a counselor/professional regarding issues relating to child with ABI.	<ul style="list-style-type: none"> • “My mum took me to a counselor... she was pretty good and made me feel a lot better” (05:22).
Dependency of injured sibling on sibling	8	Reference to the increased dependency of the child with ABI on the sibling for social contact and minding. Chosen or encouraged by parents.	<ul style="list-style-type: none"> • “I stay at home with my brother, look after him...” (24:3). • “I try to include him with most of the things I do with my friends” (18:27).
Distress at parent’s sorrow	3	Reference to feeling distress at the knowledge that parents were not coping and out of control.	<ul style="list-style-type: none"> • “...Whenever my mum gets upset, I get upset” (05:9-10). • “Seeing my parents was the worst thing, like just seeing how they were” (06:38).
Embarrassed	13	Reference to being embarrassed about the child with ABI behavior, especially in front of friends and community.	<ul style="list-style-type: none"> • “He acts a bit [inappropriately] in public, like it’s a bit embarrassing” (06:27). • “It’s embarrassing – like I have to apologize after her in shops – say ‘sorry for that, she had an accident and that’. Just feel embarrassed.” (03:10).
Emotional volatility/turmoil (ICU)	5	Reference to feeling moody and volatile as well as in emotional turmoil.	<ul style="list-style-type: none"> • “I was just always pretty easily moody” (03:2). • “I was always crying a lot of the time, frustrated and sad and I don’t know” (22:28-29).

APPENDIX L Continued

Code/Concept (and context)	N	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Exclusive experience	3	Idea that no one, unless they have been through it, understand what siblings go through.	<ul style="list-style-type: none"> “...You’ve got to experience it...” (03:11).
Extended support (ICU)	55	Reference to the great amount of support provided by community, family, friends, school, etc. regarding looking after siblings with day to day activities, or just listening, especially evident in hospitalization phase of the illness.	<ul style="list-style-type: none"> “My teacher used to bring casseroles around while my brother was in hospital” (07:10). “My uncle and nana took over, they made our lunch and dinner, so I suppose they took over as parents while they were up with Ross” (23:7).
Focus (ICU /home-coming -->)	25	Focus of physical and mental energy on the child with ABI (e.g. spending lots of time at hospital). Responsibility to be focused to help sibling.	<ul style="list-style-type: none"> “...I was at the hospital everyday with her for three months, every single day...I wanted to stay with my sister and try and help her out...” (03:2-3). “Try and get my mind off it – that was a very hard task because I was thinking about it constantly” (19:32).
Fragility of injured sibling	16	Reference to the perceived physical and emotional vulnerability of child with ABI to re-injury or death (from ABI and including suicide).	<ul style="list-style-type: none"> “He has already got hit by a car once and he nearly died, and if he gets hit by another car he could die” (04:13). “I don’t like it when he is vomiting...because he might choke, hurt himself somehow (17:32).
Guilt (ICU -->)	8	Siblings’ reference to feeling guilt regarding their abilities and their brother or sister’s inabilities and losses, and not being able to help them more, survivor guilt.	<ul style="list-style-type: none"> “[I felt] sadness and guilt...guilty because I was walking out on my brother” (05:12). “...It’s not very fair because he doesn’t really [go out or have friends] and I’m always going out...” (23:14).
Hope	16	Reference to the need to preserve hope and although want to know honest facts about ABI, still want hope to be preserved.	<ul style="list-style-type: none"> “They told me he has a 90% chance of dying, I don’t want to know that, I just want to keep thinking... positive” (06:57-58). “I think it is wrong that they give you such a bleak outlook and then you can have a turnout of just about perfect” (12:25).
Hope for full-recovery	9	Component of not understanding diagnosis and prognosis. Due to lack of information/ understanding, a hope or belief that the child with ABI will fully recover.	<ul style="list-style-type: none"> “I was thinking that in only a few more weeks she will come back to normal, I just kept hoping and waiting, but no...” (03:12).
Humor	2	The use of humor to alleviate the stress and cope during the hard times.	<ul style="list-style-type: none"> “We had a few laughs in there, it can’t all be serious” (06:47).

APPENDIX L Continued

Code/Concept (and context)	N	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Increased responsibility/ Sibling sacrifice	67	Resignation and restraint in incidences, events, thoughts, feelings and situations that arise for the sibling that prior to the ABI they would have reacted to and defended. Conducting behaviors in the best interest of the child with ABI to the sacrifice of the siblings' impulses/ needs. For example, letting go of issues that they would not have let go prior to the ABI onset. General reference to giving up own desires/ tendencies for well being of child with ABI. See apparent unfairness as fair.	<ul style="list-style-type: none"> • “[I have changed]...I don’t fight back as often...I just take the pain...” (15:10). • “[If] she asks me to do something and I don’t want to, I just do it anyway” (03:12)...“Bite your tongue, even if you are in the right, bite your tongue, because if you upset them, you don’t know what they are thinking” (03:21). • “...They (parents) give him a lot more money and that...but I want him (child with ABI) to have more because it is seeing him get help...so I am happy and everyone else is happy.” (06:55).
Increased tolerance/ patience/ mature/ responsible	18	Reference to becoming more patient and tolerant, mature and responsible in everyday activities with child with ABI as well as in other areas of life.	<ul style="list-style-type: none"> • “I just got more responsible with things, with heaps of different things” (04:14). • “You have to have real patience for him to talk” (04:9).
Increased understanding of disability/ increased empathy	13	Reference to being more understanding and empathic toward people with disability.	<ul style="list-style-type: none"> • “...Other kids [at the hospital] were disabled...and you got to know them pretty well, and you got to see that they were perfectly normal [people]” (12:19). • “I understand people [with disabilities]...and just treat them normally like we treat Ross” (23:19).
Intense anxiety (Hospitalization)	15	Reference to constant worry about child with ABI’s health condition, outcomes, long-term outcomes, diagnosis and prognosis.	<ul style="list-style-type: none"> • “...First week when she was in intensive care I was upset heaps. I couldn’t even sleep or nothing, I was that worried” (03:14). • “You get worried and things because you don’t know what’s going to happen...[or] how things are going to go and everything.” (07:10).
Interruption of life plans (ICU) Interruption of life plans (long-term)	25	Interruption of various parts of the siblings’ life as a result of the ABI - ICU and long-term impact. Interruption as a result of choice and/ or situation.	<ul style="list-style-type: none"> • “I couldn’t go out with friends and that on weekends, I would go up to the hospital instead” (13:13). • “If it’s like a family thing and James can’t go ‘cause he is in a wheel chair, then the whole family can’t go” (04:13).

APPENDIX L Continued

Code/Concept (and context)	N	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Jealousy	10	Envy directed toward the attention given to the child with ABI, and the perceived inequity of presents, gifts, and concessions made for them.	<ul style="list-style-type: none"> “...Russell gets something and I don't, you know, how come he gets that and I don't?” (20:9). “Annoyance... she always has to take the attention... like I sort of got jealous...” (22:22).
Latchkey/ increased responsibility (ICU + long-term)	18	Responsibility for the sibling to do more household chores, look after themselves and other siblings. Most prominent while child in hospital but evident post hospitalization.	<ul style="list-style-type: none"> “There was a lot of responsibility put on me...I had to look after my little brother and make sure that he was like eating, and I made his lunch and stuff, and get him ready for school” (10:8). “I was expected to help out, which of course I would have done anyway...” (05:19).
Less risk-taking behavior	14	Reference to being more careful with everyday activities (i.e. driving), as well as being more cautious with activities involving even a small element of risk (bike-riding, going on rides at a theme park). Sensitive of risks in everyday activities and heightened expectation things are likely and probable to go wrong, even if having fun.	<ul style="list-style-type: none"> “...I probably think ahead more in some things...” (23:12). “I like going on the <i>Tower of Terror</i> but I am scared that the park will have a blackout then the tower will crash...what happens then?” That sort of scares me a bit. And, from just walking around when its raining...just because I am standing up it might attract lightening [before the accident] I still thought it but not as much, not as near as much.” (19:20).
Life/ death (ICU)	16	Reference to having information (direct or indirect) that their brother or sister had a high chance of dying.	<ul style="list-style-type: none"> “...The doctors used to say ‘Ah, don't be surprised if he is not alive tomorrow’, stuff like that because he (I.S) was really bad (05:15). “... [She] was told that she was going to die two or three times...” (19:6).
Lonely/Isolated (ICU)	6	Feeling isolated and lonely (as a result of the loss of parental time and attention while child in hospital and short time after).	<ul style="list-style-type: none"> “I felt lonely because mum was always at the hospital...” (07:7). “When May was in hospital I felt very lonely...” (19:29).
Loss of interest/ concentration (ICU)	19	Loss of interest in activities, friends, school and inability to concentrate on tasks due to worry and anxiety.	<ul style="list-style-type: none"> “I wasn't paying much attention at school because I was thinking about Costa (sibling with ABI) more than school work” (17:16). “The school work wasn't hard, but I just couldn't concentrate on it, I couldn't get right into it like I can now (it was) really, really irritating” (05:13).

APPENDIX L Continued

Code/Concept (and context)	N	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Loss of parental attention (ICU)	33	Loss emotional attention and time from parents (mom/ dad or both) to siblings since ABI onset. Parent focus on child with ABI. Parents physically and emotionally absent. Siblings miss parents. Most prevalent while child in hospital.	<ul style="list-style-type: none"> • “I got to see them a little bit except some nights they would stay up there with Keith and we would just have one parent...I’d rather them all home” (13:12). • “The first three weeks or so there was always one of them (parents) there (at the hospital).” (12:22).
Loss of reciprocity	3	Effort for the relationship (even in cases where relationship is said to be closer) is one-sided from the sibling’s point of view.	<ul style="list-style-type: none"> • “I give him things and then I go and ask him and he tells me where to go” (06:35). • “He never wants to play any games” (04:9).
Loss of sibling relationship	21	Grieve and miss “old” sibling. Reference to not being able to partake in conversation and activities as much as prior to the ABI.	<ul style="list-style-type: none"> • “I’m unhappy, sad, because he will never be the same again” (14:7). • “...He can’t play around with you much anymore, things like that” (15:8). • “...You just want it to be the way it was” (06:35-36).
Loyalty to injured sibling	9	Sense of standing up for child with ABI.	<ul style="list-style-type: none"> • “This one friend that is not my friend anymore because he always says things about Max... like Max is dumb too” • “I get annoyed if they something about her because I think ‘it’s my sister” (03:6).
Miss sibling/ reminders of loss	12	Reference to missing and grieving the personality and interaction with the child with ABI since the changes.	<ul style="list-style-type: none"> • “When I see them with their sister... and mine was in hospital...it got me upset a bit” (03:3). • “Unhappy, sad...because I know he will never be the same again.” (14ms13: 7).
Noting and Fighting the injustice	5	Noticing the change in attention, etc. Rebelling, fighting, attention seeking in response to the changes. Challenging the change.	<ul style="list-style-type: none"> • “...I found the rules and broke them....” (100fs35) • “At the start I would stir her ...and... we used to start fighting (03:3). • “I’m a major attention seeker (18:17).
Open communication	10	Implied that talking to parent/ counselor/ friend/ supportive listener helped sibling to feel better.	<ul style="list-style-type: none"> • “I face them (problems) and sort the problem out and talk to mum about it” (18:36). • “I went to the counselor in sort of a rage and mum threw me into [her office to] talk to her and then I sort of came out better. (22:46).
Over protective parents	6	Parents more protective of all children since the ABI. Implicit in message the idea that world not safe. Over protective of child with ABI. Overt parental worry for child with ABI.	<ul style="list-style-type: none"> • “Mum doesn’t like me walking up the streets... (23:20). • “Because something happened to Bob that makes mum and dad overly protective” (23:11).

APPENDIX L Continued

Code/Concept (and context)	N	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Parental favoritism	24	Manifestation of the loss of time and attention experienced in hospital stage. Continuation of the loss of emotional and physical energy from parents as a result of the child's on-going demands and needs. Perception that child with ABI is closer to parents and gets more rewards and concessions.	<ul style="list-style-type: none"> “...I am angry at him, but not that angry, because sometimes when I want to like be with mum, he is always first because he had his injury.” (04:10). “Mum yells at her a lot, but she doesn't yell at her as much as me” (10:16-17).
Parents perceived as not coping	10	Reference to the recognition that parents were distressed and out of control of the situation and did not have answers.	<ul style="list-style-type: none"> “...My mum...was always upset” (05:9). “My mum didn't go to the hospital for the first week - she was too worried” (03:18).
Pedestal	5	Similar to halo effect. Perception that prior to the ABI the child with ABI was 'perfect'. Also apparent in post injury.	<ul style="list-style-type: none"> “[Prior to the accident] she was perfect... She'd buy me stuff, give me money whenever I wanted, run me anywhere...” (03:10). “When he was younger he was really smart, he could talk really fast and run really fast” (04:14).
Please others	7	Good helpful deeds for others, sometimes doing things for others to the detriment of own wishes.	<ul style="list-style-type: none"> “[There was a guy in hospital at the same time] so I went and got him a card just to let him know that a few good things can happen, it can't be all bad otherwise it is no help for them at all.” (06:61). “I would rather be training and playing with my friends [in a lower league], [but I keep playing in the top grade] just mainly to keep everyone happy” (03:7).
Positive reframe	5	Viewing the situation in a positive light, focusing on what have got, not what have lost.	<ul style="list-style-type: none"> “It's not that bad, you cope with it and it's nothing compared to what could have happened” (06:58). “...She was one of the lucky ones...” (03:21).
Positive thinking	4	Focusing thoughts on the positive, best future outcome possibilities as a means of coping.	<ul style="list-style-type: none"> “...You have to think positive or you just sit there and you cry and you are just depressed. You think positive and it gets you through it.” (06:18-19).

APPENDIX L Continued

Code/Concept (and context)	N	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Post traumatic symptomology (witness + ICU)	6	Symptoms as a result of witnessing the event and seeing siblings in hospital with foreign equipment attached. Included nightmares, flashbacks, intrusive thoughts	<ul style="list-style-type: none"> “... The first few weeks I just had the thing of seeing her get hit by the car go through my head like ninety percent of the time.” (PP:13-14). “It was scary, yeah daunting, it still comes back and you still think about it and you still feel it... (18:16)...That (the accident) all comes back in black and white all the time” (18:18-19).
Protective parental role	33	Reference to checking on, keeping an eye and ear on child with ABI. Encouraging child to do rehabilitation, physically and emotionally protecting them, making concessions for them, and verbally giving instruction about the safety/ appropriateness of their actions.	<ul style="list-style-type: none"> “You had to watch him all day, everyday in case he killed himself, and now, if he gets really fired up he'll try” (18:35). “I usually tell him to stop going that fast...with his wheel chair, I tell him to go slow and like go on the side of the road and not go really far...” (04:13). “I always look out for my brother and give him money whenever he wants, it's better than him going off and doing something stupid because he is depressed.” (06:10-11).
Reassurance	12	Reference to reassurance, especially from parents, that the child with ABI will be all right and is getting good medical care – a means of coping.	<ul style="list-style-type: none"> “[What helped me] was my family...just being there and saying everything thing is going to be all right” (06:65). “[It helps to say] don't stress over it...it will be okay, the doctors know what they are doing.” (22:45).
Respite	26	Time out/ relief provided from physical activity such as sport, school, etc.	<ul style="list-style-type: none"> “...I try not to worry about it too much...I'm doing a lot of sport and enjoying school” (18:18-19). “School was a very good distraction” (12:15).
Responsibility for the well-being family (ICU)	3	Siblings' reference to their perceived role of helping the family feel better during the child's hospitalization.	<ul style="list-style-type: none"> “If your parents see you crying then they get upset for you...so I try and keep the spirit going...then everyone has a good vibe” (06:19).
Responsibility for the well-being of the family (long-term)	14	Siblings' reference to their perceived role of helping/ protecting their family (child with ABI and parents)	<ul style="list-style-type: none"> “I try to protect him because I don't want to have to go through that again” (06:38).
Sad	22	Reference to feeling sad and upset about everything that happened from the time of onset and onwards.	<ul style="list-style-type: none"> “I'm sad, [about the change in our relationship] it means you are upset ... it's upsetting and stuff” (14:6-7). “Sometimes I thought I was going to cry...very sad...I wanted it to be over” (13:14).

APPENDIX L Continued

Code/Concept (and context)	N	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Self-blame	15	Attribution of blame to self for causing or not preventing the child from sustaining ABI, short and long-term.	<ul style="list-style-type: none"> “People try to tell me that it’s not my fault but I don’t listen...I don’t really think it is, I sort of do and I sort of don’t.” (18:19). “...I blamed all of myself...because I could have done something to have prevented him from hitting (his head)...”(20:6).
Shock (ICU + witness)	8	Disbelief, inability to comprehend situation, jolt to system. Explicit use of word shock	<ul style="list-style-type: none"> “...Yeah everyone’s emotions were going a bit whacked, sort of like shock, like hitting a brick wall. I was like, I don’t know, I can’t think of it...it was just like you know, stop please!” (22:29). “I just thought, what’s this? Is this my brother?” (05:11). “...She was in ICU and I was just like oh my God!” (22:21).
Sibling bond	7	Love and bond. Pride in child with ABI.	<ul style="list-style-type: none"> “He is more annoying than ever but I love him and I stand up for him” (20:11). “He is my brother and he is worth helping” (05:19).
Significant time	29	Reference to the significance of the onset of the ABI and as a mark in time where their lives changed significantly – stress and turmoil.	<ul style="list-style-type: none"> “Mary being hit by a car...would have to get number one, out of ten it was a pretty shitty time, I’d say ten” (12:10). “The whole family just changed automatically” (05:9).
Solitude/ space	3	Need for space.	<ul style="list-style-type: none"> “There were times when I wanted [everyone] to just go away” (06:39).
Sorrow for Parents	6	Reference to feeling empathy and sorrow for their parents’ distress.	<ul style="list-style-type: none"> “Poor dad he has copped a lot from the years” (05:20). “I felt sorry for dad...I felt sorry for dad and mum really” (03:14).
Sorrow for sibling (ICU (1) and long-term)	23	Reference to and empathy for the physical/ behavioral inabilities of the child with ABI, their frustrations and serious health condition. Direct reference to feeling sorrow for child with ABI	<ul style="list-style-type: none"> “My poor brother...” (05:15). “When I see her and she is like by her self, I feel sorry for her” (10:14). “I feel sorry because he can’t come with me ...on rides” (04:10).
Spirituality	4	Belief/ faith in God/religion/spiritual outlook seen as a presence to assist in coping with the situation.	<ul style="list-style-type: none"> “I think God is watching over us...(06:16)...he is always helping us through” (06:49).
Thought avoidance	20	Reference to controlling unpleasant thoughts re ABI and attempting not to think about anything upsetting. Cognitive strategies to deflect negative thoughts.	<ul style="list-style-type: none"> “I try not to think about it” (24:21-22). “...I tried to think about other things, I really put an effort into thinking about other things” (12:14-15).

APPENDIX L Continued

Code/Concept (and context)	N	Definition directing coding	Example excerpts from the transcripts (including the siblings' ID number and excerpt page number)
Trial & Error	12	Process of trying different strategies to manage the changes in the family until something worked.	<ul style="list-style-type: none"> • “You just have to take it as it comes and deal with it...you pick up on it pretty quick...a couple of days and you know what’s going on.” (06:60). • “I think I just picked it up over time...” (23:18).
Unable to talk to parents	10	Discomfort talking to parents about the injury and related issues. Perceived discomfort of parents re talking to siblings fostered this discomfort.	<ul style="list-style-type: none"> • “I don’t talk to them about nothing like that (ABI)...talked to one of my mates, but that was it” (03:23). • “My parents...didn’t talk about it to me” (06:57).
Unpredictability of injured sibling.	31	Reference to the erratic, variable and unpredictable behavioral and emotional tendency of child with ABI. Includes violence, moodiness, life-threatening behavior, etc.	<ul style="list-style-type: none"> • “...His moods have changed, so it’s really hard for me to get along with him” (07:4). • “He goes real mad, he gets real mad and stuff” (11:8). • “...You don’t know what she can do. You just can’t trust her 100% yet...” (03:9).
Vivid recall of events/ trauma (witness + ICU)	31	Recall of the event of seeing sibling injured, belief that sibling dead, terror, scared, panic, attempt to seek help. Recall sibling in hospital (ICU). Highlighting the trauma of the time and of being an observer.	<ul style="list-style-type: none"> • He was [swinging] and just lets go of the rope and sort of flips head, and he came down and his head hit the tyre of the car and then bounced off the tyre of the car into the sleeper, and then into the concrete. Head first, just his head first, at some force and then he just lay there, and I was freaked. ...I started shaking him and then I dragged him over to the front steps there and he had a bit of a bleed from the back of his head, and I ran inside and [shouted] ‘Mum, mum Tim’s dead’. Because I thought he was dead, I didn’t really know. (PP:10-11). • “He was screaming and I was thinking what the hell was going on” (PP:7).
Withdrawal	20	Reference to getting oneself out of the situation at hand, physically, usually by going to room or to a friends’ house. Usually to escape conflict or stress.	<ul style="list-style-type: none"> • “I go out heaps now to get away from her if she is annoying me. I’d rather go out than fight with her...” (03:14). • “...Go to my room and just lie on my bed and just lie on my bed and listen to music... get away from it” (18:36).

APPENDIX M

Example of Memoing

Below is a brief example of how concepts were developed through memos. Many memos were written even about the concepts presented below, however, the following is just an example. To begin, an example of how first level codes were derived from transcripts is given. The following excerpts were taken from parts of an initial interview with a fourteen year old male sibling who was ten years old when his brother sustained ABI. Highlighted in bold are the codes and concepts that best represented the data in the early stages of coding. It should be noted that different readers might perceive different concepts, depending on their frame of reference.

Transcript Example

[When] we went to the hospital I would be alright until I entered the ward and then I would get really down because then I would see my brother with all these tubes hanging out of him and stuff hanging off him and you would go up to him and you wouldn't be able to touch him or anything, sometimes, if he was in intensive care, because he didn't have his eyes open - you wouldn't be able to touch him and it was just really, really sad. And when he was in intensive care, he was just...every part of his body had something wrong with it...I just said "mum I can't handle this" and walked out. **(Sad/trauma of ICU/life-death/avoid/escape).**

[My parents] were always worried about Bill...like, of course they are 'cause he has been sick. And, always worrying and just, mum and dad running around like doing car trips [to hospital and rehabilitation]...mum, she wouldn't be home for ages because she was at the hospital... So, it was just mainly the first one or two years [that I was lonely] because I never used to see mum and dad much, feeling lonely. **(Parent focus on injured sibling/sibling understanding/ sacrifice /lack of parental attention/isolation).**

[When asked to pick an emotion from a sheet of faces that expressed how he felt about this change in his life, this boy pointed to a face and said:]

It sort of looks like feeling sad, but trying to hide it so your parents don't worry. **(Bottle up).**

When Bill came home... he had changed really personality wise. Like he wasn't Bill anymore and um... **(Change in injured sibling/familiar stranger).**
...He should be in grade 11, but he is too disabled... **(Visible disability/change in injured sibling).**

APPENDIX M Continued

We used to wrestle each other a lot, kick each other, hit each other, call each other names...now we are actually, like, *really* close - we share... computers.... [We don't fight'] as much as we used to because he has only had one arm to fight so it was a disadvantage. (**Understanding sibling/ sacrifice and restraint/ change in relationship with injured sibling**).

Illustrated above is the principle of open categorizing. As described in open coding, this allowed data to be categorized into multiple places so that their context and relation to one another was highlighted. This also assisted with theoretical coding, as links between concepts were preserved. These codes were initially very descriptive, but became more conceptual as categorizing continued and memoing ideas commenced. Following is an example of a memo relating to the open coding process above. Highlighted are the thought processes behind the development of concepts and categories as well as some comments on the analyst's hidden bias.

Memo Example 1

What has really stood out from the data so far is the great amount of understanding that siblings seem to have for the **loss of attention** they receive. They seem to **sacrifice** their own needs (e.g. time with parents). This sacrifice is evident in the lack of complaining that seems to be taking place about the lack of attention they receive.

Sacrifice also seems to be evident in the **change in relationship with injured sibling**. Where siblings used to fight, they now **sacrifice** the urge to do so (see also 15ms8-9). This sacrifice also seems to relate to an understanding of the child's needs when they are sick (e.g. "[My parents] were always worried about Bill...*like, of course they are 'cause he has been sick.*"). This finding is surprising to me as I expected to hear more about feelings of jealousy, especially from young children. Only one sibling so far, however, has not discussed sacrificing. Interestingly, this sibling perceived his injured sister to have become "more mean". I also observed that her disability is "hidden". I found it difficult to see signs of ABI.

APPENDIX M Continued

It therefore seems that perhaps the concept of **sacrifice** in siblings is related to an understanding of the child's **vulnerability** that is evident from the **change in injured sibling**, such as **visible disabilities** and obvious limitations. If the child is not perceived to be different, perhaps siblings do not think that inequity is justified. They challenge the injustice. Siblings also **bottle-up** their feelings and hide them from their parents so that they do not worry. Why would siblings bottle-up? Why do siblings sacrifice, showing restraint in their interaction? What purpose does it serve?

This memo exemplifies the process of relating concepts to each other. It also shows the development of hypotheses that are continually grounded in the data. For example, the memo above suggests that perceived **vulnerability** in an injured sibling may be a condition necessary for **sacrificing** behavior regarding the interaction with their sibling. It also poses questions to be followed up in further analysis, such as, why this happens. Indeed, as analysis and memoing continued, it became apparent that the concept "*bottle-up*," which was later re-named "*emotional restraint*" was another form of sacrifice. Soon, a number of concepts (e.g. *protective parental role*, *constant contact*, etc.) emerged as other forms of sacrifice. As described above, comparing the meaning underlying these concepts revealed more about their purpose and place in the theory. For instance, that sacrificing emerged as strategies to combat further vulnerability.

One more memo is worth illustrating, however, since it highlights the importance of negative cases and how they assisted to refine the theory, eventually being responsible for highlighting the BPS process in later stages of the analysis.

APPENDIX M Continued

Memo Example 2

Sacrifice has clearly emerged as a near core category. It links and relates to most categories and their properties (concepts). It is the strategy that solves most siblings' problem (vulnerability in injured sibling, family, etc.). However, it is not quite core because it cannot explain concepts such as, **fighting the injustice**. This seems to oppose sacrifice. The data indicates siblings fight when they fail to see the fairness in the inequality (e.g. loss of parental attention). It is also usually related to a low level of exposure to the injured sibling's vulnerability. For example, sibs fight like they used to before the injury, they do what they used to do to get justice – to fix the inequality (e.g. see interview 03ms:03). Fighting was a way of sorting out problems in the sibling subsystem prior to the ABI. Following ABI, fighting, however, leads to more turmoil. This, however, seems to directly oppose the strategy and purpose of sacrifice. Or does it? What are the aims of both these strategies?

Sacrifice is trying to ensure safety, cap further turmoil, **restore a sense of equilibrium** in the family and self. **Fighting the injustice** is also a strategy to **restore a sense of equilibrium** (in light of receiving less parental attention), and old patterns that are familiar. Siblings seem to be fighting for their place in the family again – to restore a sense of belonging (as opposed to isolation), and thus emotional equilibrium. Perhaps the problem all siblings are trying to process is a loss of equilibrium. Interview 103fs:mc verifies this. I need to go back to the data to confirm this. Have I left anything out?

This memo illustrates the development of the core category, which was assisted by the exploration of what appeared to be a 'negative case'. Indeed, Glaser (1978) stated "strange data are never a source of embarrassment, in disproving a deduced hypothesis, but an excellent occasion for what they may contribute upon comparison to theoretical expansion, refinement, and enrichment of the emerging theory" (p. 38). As highlighted in the memo, re-analysis of the data was required in light of this discovery to ensure that the idea was grounded. As already described, the above concepts and categories were further integrated and analyzed to eventually result in a parsimonious theory, accounting for variability (see Chapters 5 & 6).

APPENDIX N

Evaluating a Grounded Theory

Grounded theories are judged on their *degree of fit*, *functionality*, *relevance*, and *modifiability* (Glaser, 1978). These criteria are essential, not only for understanding grounded theory, but also for minimizing potential predetermined biases and for producing an inductive theory that stays true to the population about which it wishes to discover more. The methods employed for implementing a rigorous grounded theory, and for enhancing its reliability are discussed Chapters 3 and 4, however the criterion for measuring a grounded theory is described below.

The degree of *fit* of a grounded theory concerns the extent to which categories and codes generated from the data must fit the data. The categories and codes should not be preconceived and should emerge from the data, rather than be forced on the data. Connections between the emergent categories and the data should be clear (Glaser, 1978). Further, “the theory should provide clear enough categories and hypotheses so that crucial ones can be verified in present and future research; they must be clear enough to be readily operationalized in quantitative studies when these are appropriate” (Glaser & Strauss, 1967, p. 3).

A grounded theory is also evaluated in terms of its *functionality*, or how well it *works*. For the theory to be functional, it “should be able to explain what happened, predict what will happen and interpret what is happening” (Glaser, 1978). Thus, a functional theory, should be able to “explain variation in the data, as well as the interrelationships among the constructs in a way that produces a predictive element to the theory” (Kerlin, 1998; cited in Yee, 2001, p. 12).

APPENDIX N Continued

A theory must also be *relevant* to the people it concerns by connecting to their experience of reality (Brooks, 1998; Yee, 2001). The theory should be readily understandable to academics, participants and significant laymen (Glaser & Strauss, 1967). A theory's relevance highlights its worth and is an essential component in evaluating a grounded theory.

Finally, based on the principle that the world is constantly changing, grounded theories are also judged by their capacity to be *modified* to accommodate change. Thus, new data should be incorporated into the emergent framework with ease. Importantly, data that may seem contradictory (e.g. negative cases) should also be incorporated into the emerging framework with little effort and explicated by the core category. One fundamental assumption in grounded theory is that the data is always right and "if the grounded theory requires a major overhaul of its central premises to account for new data it can be considered a poor theory" (Yee, 2001, p. 12). A grounded theory is open-ended and can be extended indefinitely. However, grounded theories should also be *parsimonious*, explaining as much variation as possible with as few main categories as possible (Yee, 2001).

REFERENCES

- Achenback, T. M., & Edelbrock, C. (1983). *Manual for the child behavior checklist and revised behavior profile*. Burlington: University of Vermont, Department of Psychiatry.
- American Psychiatric Association (1994). *Diagnostic and statistical Manual of Mental Disorders (4th ed.) Source Book*. Washington DC: American Psychiatric Association.
- Anderson, V., Fenwick, T., Manly, T., & Robertson, I. H. (1998). Attentional skills following traumatic brain injury. *Brain Injury*, 12(11), 937-949.
- Andrews, T. K., Rose, F. D., & Johnson, D. A. (1998). Social and behavioural effects of traumatic brain injury in children. *Brain Injury*, 12, 133-138.
- Annegers, J. F. (1983). The epidemiology of head trauma in children. In K. Shapiro (Ed.), *Pediatric Head Trauma* (pp. 1-10). New York: Futura.
- Annegers, J. F., Grabow, J. D., Kurland, L. T., & Laws, E. R., Jr. (1980). The incidence, causes, and secular trends of head trauma in Olmsted County, Minnesota, 1935-1974. *Neurology*, 30, 912-919.
- Appleton, R. (1998). Epidemiology – incidence, causes and severity. In R. Appleton & T. Baldwin (Eds.), *Management of Brain Injured Children* (pp. 1-10). Oxford, UK: Oxford University Press.
- Appleton, R., & Baldwin, T. (Eds.). (1998). *Management of Brain Injured Children*. Oxford, UK: Oxford University Press.
- Arroyos-Jurado, E., Paulsen, J. S., Merrell, K. W., Lindgren, S. D., & Max, J. E. (2000). Traumatic brain injury in school-age children academic and social outcome. *Journal of School Psychology*, 38(6), 571-587.
- Baker, C., Wuest, J., & Stern, P. N. (1992). Method slurring: The grounded theory/phenomenological example. *Journal of Advanced Nursing*, 17, 1355-1360.
- Baldwin, T., Nash, J., & Appleton, R. (1997). Brain (head) injury team. In R. Appleton & T. Baldwin (Eds.), *Management of Brain-Injured Children* (pp. 26-41). Oxford, UK: Oxford University Press.
- Banja, J.D. (1992). Tragedy and traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 7, 112-114.
- Bank, S. P., & Kahn, M. D. (1997). *The Sibling Bond*. New York, NY: Basic Books.

- Barbarin, O. A., Sargent, J. R., Sahler, O. J. Z., Carpenter, P. J., Copeland, D. R., Dolgin, M. J., et al. (1995). Sibling adaptation to childhood cancer collaborative study: Parental views of pre- and post-diagnosis adjustment of siblings of children with cancer. *Journal of Psychosocial Oncology*, 13(3), 1-20.
- Barin, J. J., Hanchett, J. M., Jacob, W. L., & Scott, M. B. (1985). Counseling the head injured patient. In M. Ylvisaker (Ed.), *Head injury rehabilitation: Children and adolescents* (pp. 361-383). San Diego, CA: College-Hill Press.
- Barry, P., & Clark, C. (1992). Effects of intact versus non-intact families on adolescent head injury rehabilitation. *Brain Injury*, 6, 229-232.
- Barth, J. T., Gideon, D. A., Sciara, A. D., Hulsey, P. H., & Anchor, K. N. (1986). Forensic aspects of mild head trauma. *Journal of Head Trauma Rehabilitation*, 1, 63-70.
- Basson, M. D., Guinn, J. E., McElligott, J., Vitale, R., Brown, W., & Fielding, L. P. (1991). Behavioral disturbances in children after trauma. *Journal of Trauma*, 31, 1363-1368.
- Becker, P. H. (1993). Pearls, pith, and provocation: Common pitfalls in published Grounded Theory research. *Qualitative Health Research*, 3(2), 135-139.
- Beers, S. R. (1992). Cognitive effects of mild brain injury in children and adolescents. *Neuropsychological Review*, 3, 281-320.
- Begali, V. (1992). *Head injury in children and adolescents: A resource and review for school and allied professionals* (2nd ed.). Virginia: Clinical Psychology Publishing Company, Inc.
- Bendor, S. J. (1990). Anxiety and isolation in siblings of pediatric cancer patients: The need for prevention. *Social Work In Health Care*, 14, 17-35.
- Benoliel, J. Q. (1996). Grounded theory and nursing knowledge. *Qualitative Health Research*, 6, 406-428.
- Bijur, P., Haslum, M., & Golding, J. (1990). Cognitive and behavioural sequelae of mild head injury in children. *Pediatrics*, 86, 337-344.
- Bischoff, L. G., & Tingstrom, D. H. (1991). Siblings of children with disabilities: Psychological and behavioural characteristics. *Counselling Psychology Quarterly*, 4(4), 311-321.
- Blaskey, J., & Jennings, M. (1999). Traumatic brain injury. In S. Campbell (Ed.), *Decision making in pediatric neurologic physical therapy* (pp. 84-140). New York, NY: Churchill Livingstone.

- Bloom, D. R., Levin, H. S., Ewing-Cobbs, L., Saunders, A. E., Song, J., Fletcher, J. M., et al. (2001). Lifetime and novel psychiatric disorders after pediatric traumatic brain injury. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40(5), 572-579.
- Bluebond-Langner, M. (1989). Worlds of dying children and their well siblings. *Death Studies*, 13, 1-16.
- Bluebond-Langner, M. (1996). *In the shadow of illness: Parents and siblings of the chronically ill child*. Princeton, NJ, USA: Princeton University Press.
- Blumer, H. (1978). Social unrest and collective protest. In N. Denzin (ed.), *Studies in symbolic interaction: Vol. 1*. Greenwich: SAI Press.
- Bowlby, J. (1980). *Loss: Sadness and depression. Vol. 3: Attachment and Loss*. London: Penguin Press.
- Bragg, R. M., Klockars, A. J., & Berninger, V. W. (1992). Comparison of families with and without adolescents with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 7(3), 94-108.
- Breslau, N. (1982). Siblings of disabled children: Birth order and age-spacing effects. *Journal of Abnormal Child Psychology*, 10, 85-96.
- Breslau, N., & Prabucki, K. (1987). Siblings of disabled children: Effects of chronic stress in the family. *Archives of General Psychiatry*, 44, 1040-1046.
- Brooks, D. N. (1991). The head-injured family. *Journal of Clinical and Experimental Neuropsychology*, 13, 155-188.
- Brooks, I. J. (1998). *Weighing up change: A grounded theory explaining the response of middle managers to organisational change*. Unpublished PhD Dissertation, University of Canterbury.
- Brooks, N., Campsie, L., Symington, C., Beattie, A., & McKinlay, W. (1986). The five year outcome of severe blunt head injury: A relative's view. *Journal of Neurology, Neurosurgery, and Psychiatry*, 49, 664-700.
- Brown, G., Chadwick, O., Shaffer, D., Rutter, M., & Traub, M. (1981). A prospective study of children with head injuries: II. Psychiatric sequelae. *Psychological Medicine*, 11, 49-62.
- Bruce, E. J., & Schultz, C. L. (2001). *Nonfinite loss and grief. A psychoeducational approach*. Sydney, Australia: MacLennan & Petty Pty Limited.
- Burton, S. L. (1987). Children and siblings of the handicapped. In A. Thomas & J. Grimes (Eds.), *Children's Needs: Psychological Perspectives* (pp. 544-560). Washington, DC: National Association of School Psychologists.

- Cadman, D., Boyle, M., & Offord, D. (1988). The Ontario Child Health Study: Social adjustment and mental health of siblings of children with chronic health problems. *Developmental and Behavioural Pediatrics*, 9, 117-121.
- Carney, J., & Gerring, J. (1990). Return to school following severe closed head injury: A critical phase in pediatric rehabilitation. *Pediatrician*, 17, 222-229.
- Carpenter, P. J., & Sahler, O. J. Z. (1991). Sibling perception and adaptation to childhood cancer. In J. H. Johnson & S. Bennett Johnson (Eds.), *Advances in child health psychology* (pp. 193-205). Gainesville: University of Florida Press.
- Case, R. (1992). The role of the frontal lobes in the regulation of cognitive development. *Brain and Cognition*, 20, 51-73.
- Catalano, T. (2001). *Coping resources identified by participants with stroke: A qualitative study*. Unpublished Thesis. Griffith University, Queensland, Australia.
- Cattelani, R., Lombardi, F., Brianti, R., & Mazzucchi, A. (1998). Traumatic brain injury in childhood: Intellectual, behavioural and social outcome into adulthood. *Brain Injury*, 12(4), 283-296.
- Chadwick, O., Rutter, M., Brown, G., Shaffer, & Traub (1981). A prospective study of children with head injuries II. Cognitive sequelae. *Psychological Medicine*, 11, 49-61.
- Chesler, M. A., Allswede, J., & Barbarin, O. O. (1992). Voices from the margin of the family: Siblings of children with cancer. *Journal of Psychosocial Oncology*, 9, 19-42.
- Cicirelli, V. G. (1991). Sibling relationships in adulthood. In S. P. Pfeifer, & M. B. Sussman (Eds.), *Families: Intergenerational and generational connections* (pp. 291-310). New York: Haworth Press.
- Cicirelli, V. C. (1995). *Sibling relationships across the lifespan*. New York, NY: Plenum Press.
- Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*, 20, 37-46.
- Cohen, D., Freidrich, W., Jaworski, T., Copeland, D., & Pendergrass, T. (1995). Pediatric cancer: predicting sibling adjustment. *Journal of Clinical Psychology*, 50, 303-319.
- Coster, W. J., Haley, S., & Baryza, M. J. (1994). Functional performance of young children after traumatic brain injury: A six-month follow-up study. *American Journal of Occupational Therapy*, 48, 211-218.

- Crnic, K. A., & Leconte, J. M. (1986). Understanding sibling needs and influences. In R. R. Fewell & P. F. Vadasy (Eds.), *Families of handicapped children: Needs and supports across the life span* (pp. 75-98). Austin, Texas: Pro-Ed.
- Cronin, A. F. (2001). Traumatic brain injury in children: Issues in community function. *The American Journal of Occupational Therapy*, 55(4), 377-384.
- Cuskelly, M. (1999). Adjustment of siblings of children with a disability: Methodological issues. *International Journal for the Advancement of Counselling*, 21(2), 111-124.
- Dalby, P. R., & Obrzut, J. E. (1991). Epidemiological characteristics and sequelae of closed head injured children and adolescents: A review. *Developmental Neuropsychology*, 7, 35-68.
- Damiani, V. B. (1999). Responsibility and adjustment in siblings of children with disabilities. Update and review. *Families in Society*, 80(1), 34-40.
- Davis, F. (1963). *Passage Through Crisis: Polio Victims and their Families*. New York, NY: Bobbs-Merrill.
- Davis, B. H. (1987). Disability and grief. *The Journal of Contemporary Social Work*, June, 352-357.
- Degeneffe, C. E. (2001). Family caregiving and traumatic brain injury. *Health & Social Work*, 26(4), 257-268.
- Denzin, N. K. (1989). *Interpretive Interactionism. Applied Social Research Methods Series: Vol. 16*. Newbury Park: Sage.
- de Vaus, D. A. (1991) *Surveys in Social Research* (3rd ed.). London, Allen and Unwin.
- DiScala, C., Osberg, J., Gans, B., Chin, L., & Grant, C. (1991). Children with traumatic head injury: Morbidity and post acute treatment. *Archives of Physical Medicine and Rehabilitation*, 72, 662-666.
- DiScala, C., Osberg, J., & Savage, R. (1997). Children hospitalized for traumatic brain injury: Transition to post acute care. *Journal of Head Trauma Rehabilitation*, 12, 1-10.
- Doka, K.J. (Ed.). (1989). *Disenfranchised grief*. Lanham, MD: Lexington Books.
- Drotar, D., & Crawford, P. (1985). Psychological adaptation of siblings of chronically ill children: Research and practical implications. *Developmental and Behavioral Pediatrics*, 6, 355-362.

- Drotar, D., Crawford, P., & Bush, M. (1984). The family context of childhood chronic illness: Implications for psychosocial intervention. In M. Eisenberg (Ed.), *Chronic Illness and Disability Through the Lifespan*. New York, NY: Springer.
- Eaves, Y. D. (2001). A synthesis technique for grounded theory data analysis. *Journal of Advanced Nursing*, 35(5), 654-663.
- Ergh, T. C., Rapport, L. J., Coleman, D., & Hanks, R. A. (2002). Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *The Journal of Head Trauma Rehabilitation*, 17(2), 155.
- Ewing-Cobbs, L., Levin, H. S., & Fletcher, J. M. (1998). Neuropsychological sequelae after pediatric traumatic brain injury: Advances since 1985 (2nd Ed.) In M. Ylvisaker (Ed.), *Traumatic brain injury rehabilitation: Children and adolescents* (pp. 11-26). Boston, MA: Butterworth-Heinemann.
- Fagerhaugh, S. Y. (1995). Analyzing data for basic social process. In B. G. Glaser (Ed.), *Grounded Theory 1984-1994* (pp. 173-187). California: Sociology Press(2).
- Fanos, J. H., & Nickerson, B. G. (1991). Long-term effects of sibling death during adolescence. *Journal of Adolescent Research*, 6(1), 70-82.
- Farber, B. (1960). Family organization and crises: Maintenance of integration in families with a severely mentally retarded child. *Monograph of the Society of Research in Child Development*, 25(1), (Serial No. 75).
- Fay, G. C., Jaffe, K. M., Polissar, N. L., Liao, S., Rivara, J. B., & Martin, K. M. (1994). Outcome of pediatric traumatic brain injury at three years: A cohort study. *Archives of Physical Medicine and Rehabilitation*, 75, 733-741.
- Ferrari, M. (1984). Chronic illness: Psychosocial effects of siblings of chronically ill boys. *Journal of Child Psychology and Psychiatry*, 25, 459-476.
- Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T., & Szatmari, P. (1996). Risk and protective factors affecting the adjustment of siblings of children with chronic disabilities. *Journal of the American Academy of Child Adolescent Psychiatry*, 35(11), 1532-1541.
- Fletcher, J. M., Ewing-Cobbs, L., Miner, M. E., Levin, H. S., & Eisenberg, H. M. (1990). Behavioural changes after closed head injury in children. *Journal of Consulting and Clinical Psychology*, 58, 93-98.
- Florian, V., & Katz, S. (1991). The other victims of traumatic brain injury: consequences for family members. *Neuropsychology* 5(4), 267-279.
- Florian, V., Katz, S., & Lahav, V. (1989). Impact of traumatic brain damage on family dynamics and functioning: A review. *Brain Injury* 3(3), 219-233.

- Fortune, N., & Wen, X. (1999). *The definition, incidence and prevalence of acquired brain injury in Australia*. Canberra: Australian Institute of Health and Welfare.
- Foster, M. A., & Carlson-Green, B. (1993). The transition from hospital to home: Family readjustment and response to therapeutic intervention following childhood-acquired brain injury. *Family Systems Medicine*, 11(2), 173-180.
- Frankl, V. (1985). *Man's Search for Meaning*. Boston, MA: Washington Square Press.
- Frankowski, R. F. (1985). Head injury mortality in urban populations and its relation to the injured child. In B. F. Brooks (Ed.), *The injured child* (pp. 20-29). Austin: University of Texas Press.
- Frankowski, R. F., Annegers, J. F., & Whitman, S. (1985). Epidemiological and descriptive studies: Part I. The descriptive epidemiology of head trauma in the United States. In D. P. Becker & J. T. Povlishock (Eds.), *Central nervous system trauma status report- 1985* (pp. 33-43). Bethesda, MD: National Institute of Neurological and Communicative Disorders and Stroke, National Institutes of Health.
- Gan, C., & Schuller, R. (2002). Family system outcome following acquired brain injury: Clinical and research perspectives. *Brain Injury*, 16(4), 311-322.
- Geertz, C. (1973). Thick description: Towards an interpretive theory of culture. In C. Geertz, *The Interpretation of Cultures* (pp. 3-30). New York: Basic Books.
- Geldard, K., & Geldard, D. (1998). *Counselling children: A practical introduction*. London, UK: Sage Publications.
- Gill, D. J., & Wells, D. L. (2000). Forever different: Experiences of living with a sibling who has a traumatic brain injury. *Rehabilitation Nursing*, 25(2), 48-52.
- Glaser, B. G. (1978). *Theoretical Sensitivity*. Mill Valley, CA: Sociological Press.
- Glaser, B. G. (1992). *Emergence vs forcing: Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. (1995). *Grounded Theory: 1984-1994*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Goldstein, F. C., & Levin, H. S. (1987). Epidemiology of pediatric head injury: Incidence, clinical characteristics and risk factors. *Journal of Learning Disabilities*, 20, 518-525.

- Grattan, L. M., & Eslinger, P. J. (1991). Frontal lobe damage in children and adults: A comparative review. *Developmental Neuropsychology* 7, 283-326.
- Grbich, C. (1999). *Qualitative Research in Health: An introduction*. St Leonards, NSW: Allen & Unwin.
- Grossman, F. K. (1972). *Brothers and sisters of retarded children*. Syracuse, NY: Syracuse University Press.
- Guba (1981). *Grounded theory*. Mill Valley, California: The Sociology Press.
- Guthrie, E., Mast, J., Richards, P., McQuaid, M., & Pavlakis, S. (1989). Traumatic brain injury in children and adolescents. *Neurologic Disorders: Developmental and Behavioral Sequelae*, 8(4), 807-826.
- Hall, K. M., Karzmark, P., Stevens, M., Englander, J., O'Hare, P., & Wright, J. (1994). Family stressors in traumatic brain injury: A two-year follow-up. *Archives of Physical Medicine and Rehabilitation*, 75, 876-884.
- Harvey, A. G., Brewin, C. R., Jones, C., & Kopelman, M. D. (2003). Coexistence of posttraumatic stress disorder and traumatic brain injury: Towards a resolution of the paradox. *Journal of the International Neuropsychological Society*, 9(4), 663-676.
- Havermans, T., & Eiser, C. (1994). Siblings of a child with cancer. *Child Care Health and Development*, 20, 309-322.
- Healy, J. M., Stewart, A. J., & Copeland, A. P. (1993). The role of self-blame in children's adjustment to parental separation. *Personality and Social Psychology Bulletin*, 19(3), 279-289.
- Hearn, L. (2000). *Acquired brain injury and Queensland: Incidence, prevalence, areas of need, and models of response*. Brain Injury Association of Queensland.
- Horwitz, W. A., & Kazak, A. E. (1990). Family adaptation to childhood cancer: Sibling and family systems variables. *Journal of Clinical Child Psychology*, 19, 221-228.
- Houtzager, B. A., Grootenhuis, M. A., & Last, B. F. (1999). Adjustment of siblings to childhood cancer: A literature review. *Supportive Care in Cancer*, 7(5), 302-320.
- Hutchinson, S. (1986). Grounded theory: The method. In P. L. Munhall, & C. J. Oiler (Eds.), *Nursing research: A qualitative perspective* (pp. 111-130). Norwalk, CT: Appleton-Century-Crofts.
- Jacobs, H. E. (1988). The Los Angeles head injury survey: Procedures and initial findings. *Archives of Physical Medicine and Rehabilitation*, 69, 425-431.

- Janoff-Bulman, R. (1979). Characterological versus behavioral self-blame: Inquiries into depression and rape. *Journal of Personality and Social Psychology*, 37(10), 1798-1809.
- Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*, New York: Free Press.
- Janoff-Bulman, R., & Wortman, C. B. (1977). Attributions of blame and coping in the "real world": Severe accident victims react to their lot. *Journal of Personality and Social Psychology*, 35(5), 351-363.
- Joseph, S. A., Brewin, C. R., Yule, W., & Williams, R. (1993). Causal attributions and post traumatic stress in adolescents. *Journal of Child Psychology and Psychiatry*, 34(2), 247-253.
- Kaplan, S. P. (1991). Psychosocial adjustment three years after traumatic brain injury. *The Clinical Neuropsychologist*, 5(4), 361-369.
- Kaplan, S., & Questad, K. (1980). Client characteristics in rehabilitation studies. *Journal of Applied Rehabilitation Counselling*, 11, 165-168.
- Kaufmann, P. M., Fletcher, J. M., Levin, H. S., Harvey, S., Miner, M.E. et al. (1993). Attentional disturbance after pediatric closed head injury. *Journal of Child Neurology*, 8, 348-353.
- Kay, T., & Cavallo, M. (1994). The family system: Impact, assessment, and intervention. In J. M. Silvers, S. C. Yudofsky, & R. E. Hales (Eds.), *Neuropsychiatry of traumatic brain injury* (pp. 533-567). Washington DC: American Psychiatric Press.
- Kehle, T. J., Clark, E., & Jenson, W. R. (1997). Interventions for children with traumatic brain injury. *Journal of Learning Disabilities*, 29, 633-690.
- Kendall, E., & Buys, N. (1998). An integrated model of psychosocial adjustment following acquired disability. *Journal of Rehabilitation*, July/August/September, 16-20.
- Kendall, J. (1999). Sibling accounts of attention deficit hyperactivity disorder (ADHD). *Family Process*, 38(1), 117-136.
- Kerlin, B. A. (1998, February). *Pursuit of the Ph.D: Is it Good for your Health?* Paper presented at the 4th International Multidisciplinary Qualitative Health Research Conference, Vancouver, Canada.
- King, N. (1994). *The qualitative research interview*. London: Sage Productions.
- Kinsella, G., Prior, M., Sawyer, M., Ong, B., Murtagh, D., Eisenmajer, R., et al. (1997). Predictors and indicators of academic outcome in children 2 years following traumatic brain injury. *Journal of the International Neuropsychological Society*, 3, 608-616.

- Kinsella, G., Ong, B., Murtagh, D., Prior, M., & Sawyer M. (1999). The role of the family for behavioural outcome in children and adolescents following traumatic brain injury. *Journal of Consulting and Clinical Psychology*, 67(1), 116-123.
- Kirk, J., & Miller, M. L. (1986). *Reliability and validity in qualitative research*. Beverly Hills, CA: Sage Publications.
- Kirkwood, M., Janusz, J., Yeates, K. O., Taylor, H. G., Wade, S. L., Stancin, T., et al. (2000). Prevalence and correlates of depressive symptoms following traumatic brain injuries in children. *Child-Neuropsychology*, 6(3), 195-208.
- Klonoff, H., Clark, C., & Klonoff, P. S. (1993). Long term outcome of head injuries: a 23 year follow up study of children with head injuries. *Journal of Neurology, Neurosurgery and Psychiatry*, 56, 410-415.
- Kneipp, S. (1996). Providing support to siblings of children with ABI. In G. Singer, A. Glang, & J. M. Williams (Eds.), *Children with ABI: Educating & supporting families*. Baltimore, MD: Paul H Brookes Publishing Company.
- Knights, R. M., Ivan, L. P., Ventrueyra, E. C. (1991). The effects of head injury in children on neuropsychological and behavioural functioning. *Brain Injury*, 5, 339-351.
- Kosciulek, J. F. (1994). Dimensions of family coping with head injury. *Rehabilitation Counselling Bulletin*, 37(3), 244-258.
- Kosciulek, J. F., & Lustig, D. C. (1999). Differentiation of three brain injury family types. *Brain Injury*, 13(4), 245-254.
- Kosciulek, J. F., McCubbin, M. A., & McCubbin, H. I. (1993). A theoretical framework for family adaptation to head injury. *Journal of Rehabilitation*, July/August/September, 40-45.
- Kramer, R. F. (1984). Living with childhood cancer: Impact on healthy siblings. *Oncology Nursing Forum*, 11, 44-51.
- Kraus, J. F. (1987). Epidemiology of head injury (2nd Ed.) In P. R. Cooper (Ed.), *Head Injury* (pp. 1-19). Baltimore, MD: Williams & Wilkins.
- Kreutzer, J. S., Marwitz, J. H., & Kepler, K. (1992). Traumatic brain injury - family response and outcome. *Archives of Physical Medicine and Rehabilitation*, 73(8), 771-778.
- Kupst, M.J. (1986). Coping in siblings of children with serious illness. In S.M. Auerbach & A.L. Stolberg (Eds.), *Crisis Intervention with children and families: The Series in Clinical and Community Psychology* (pp. 173-189). Washington DC: Hemisphere Publishing Corp.

- Langner, T. S., Gersten, J. C., McCarthy, E. D., Eisenberg, J. G., Green, E. L., Hersen, J. H., et al. (1976). A screening inventory for assessing psychiatric impairment in children 6 to 18. *Journal of Consulting and Clinical Psychology, 44*, 286-296.
- Lazar, M. R., & Menaldino, S. (1995). Cognitive outcome and behavioural adjustment in children following traumatic brain injury: A developmental perspective. *Journal of Head Trauma Rehabilitation, 10*, 55-63.
- Lehmkuhl, G. & Thoma, W. (1990). Development in children after severe head injury. In A. Rothenberger (Ed.), *Brain and Behavior in Child Psychiatry* (pp. 267-282). Berlin: Springer-Verlag.
- Levin, H. S., Culhane, K. A., & Mendelsohn, D., Matthew, L., et al. (1993). Cognition in relation to magnetic resonance imaging in head injured children and adolescence. *Archives of Neurology, 50*, 897-905.
- Lezak, M. D. (1986). Psychological implications of traumatic brain damage for the patient's family. *Rehabilitation Psychology 31*(4) 241-250.
- Lezak, M. D. (1987). Relationships between personality disorders, social disturbances, and physical disability following traumatic brain injury. *Journal of Head Trauma Rehabilitation, 2*, 57-69.
- Lezak, M. D. (1988). Brain damage is a family affair. *Journal of Experimental Neuropsychology, 10*(1), 111-123.
- Lincoln, S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Linn R. T., Allen K., & Willer B. S. (1994). Affective symptoms in the chronic stage of traumatic brain injury: A study of married couples. *Brain Injury, 8*(2), 135-147.
- Livingston, M., & Brooks, D. (1988). The burden of families of the brain injured: A review. *Journal of Head Trauma Rehabilitation, 3*, 6-15.
- Llewellyn, G. (1996). Qualitative Research. In F. Stein & S. K. Cutter (Eds.), *Clinical research in allied health and special education* (pp. 411-423). San Diego, CA: Singular Publication Group.
- Lobato, D. (1983). Siblings of handicapped children: A review. *Journal of Autism and Developmental Disorders, 13*(4), 347-364.
- Lobato, D., Barbour, L., Hall, L. J., & Miller, C. T. (1987). Psychosocial characteristics of preschool siblings of handicapped and nonhandicapped children. *Journal of Abnormal Child Psychology, 15*(3), 329-338.
- Lobato, D., Faust, D., & Spirito, A. (1988). Examining the effects of chronic disease and disability on children's sibling relationships. *Journal of Pediatric Psychology, 13*(3), 389-407.

- Lobato, D.J., & Kao, B.T. (2002). Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. *Journal of Pediatric Psychology*, 27 (8), 711-716.
- Lofland, J., & Lofland, L. H. (1984). *Analyzing social settings: A guide to qualitative observation and analysis* (2nd ed.). Belmont, CA: Wadsworth Publishing Company.
- Luiselli, J. K., Dion, D., Hammil, E., Potoczny-Gray, A., Savage, R., & Sherak, D. L. (2000). Psychiatric hospitalization and school and community adjustment of children and adolescents with acquired brain injury. *Journal of Child and Family Studies*, 9, 481-489.
- Maitz, E. A., & Sachs, P. R. (1995). Treating families of individuals with traumatic brain injury from a family systems perspective. *Journal of Head Trauma Rehabilitation*, 10(2), 1-11.
- Martin, D. A. (1990). Family issues in traumatic brain injury. In E. D. Bigler (Ed.), *Traumatic brain injury: Mechanisms of damage, assessment, intervention, and outcome* (pp. 381-394). Austin, TX: pro-ed.
- Mateer, C. A., Kerns, K. A., & Eso, K. L. (1997). Management of attention and memory disorders following traumatic brain injury. In E. D. Bigler, E. Clark, & J. E. Farmer (Eds.), *Childhood traumatic brain injury: Diagnosis, assessment and intervention* (pp. 153-175). Austin, TX: pro-ed.
- Mateer, C. A., & Williams, D. (1991). Effects of frontal lobe injury in childhood. *Developmental Neuropsychology*, 7, 359-376.
- Maurer, J. (1991). Special issues for a sibling. In J.M. Williams & T. Kay (Eds.), *Head Injury: A Family Matter* (pp. 29-33). Baltimore: Paul H Brookes Publishing Co.
- Max, J. E., Smith, W. L., Sato, Y., Mattheis, P. J., Castillo, C. S., Lindgren, S. D., et al. (1997a). Traumatic brain injury in children and adolescents: Psychiatric disorders in the first three months. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36(1), 94-102.
- Max, J. E., Robin, D. A., Lindgren, S. D., Smith, W. L., Sato, Y., Mattheis, P. J., et al. (1997b). Traumatic brain injury in children and adolescents: Psychiatric disorders at two years. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36(9), 1278-1285.
- Max, J. E., Koele, S. L., Lindgren, S. D., Robin, D. A., Smith, W. L., Sato, Y., et al. (1998a). Adaptive functioning following traumatic brain injury an orthopedic injury: A controlled study. *Archives of Physical Medicine and Rehabilitation*, 79, 893-899.
- Max, J. E., Lindgren, S. D., Knutson, C., Pearson, C. S., Ihrig, D., & Wellborn, A. (1998b). Child and adolescent traumatic brain injury: Correlates of injury severity. *Brain Injury*, 12, 31-40.

- Max, J. E., Roberts, M. A., Koele, S. L., Lindgren, S. D., Robin, D. A., Arndt, S., et al. (1999). Cognitive outcome in children and adolescents following severe traumatic brain injury: influence of psychosocial, psychiatric and injury-related variables. *Journal of the International Neuropsychological Society*, 5(1), 58-68.
- Max, J. E., Koele, S. L., Castillo, C. S., Lindgren, S. D., Arndt, S., Bokura, H., et al. (2000). Personality change disorder in children and adolescents following traumatic brain injury. *Journal of International Neuropsychological Society*, 6, 279-289.
- Max, J. E., Robertson, B. A., & Lansing, A. E. (2001). The phenomenology of personality change due to traumatic brain injury in children and adolescents. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 13(2), 161-170.
- Mayes, S. D., Pelco, L. E., & Campbell, C. J. (1989). Relationships among pre- and post-injury intelligence, length of coma, and age in individuals with severe closed head injuries. *Brain Injury*, 3, 301-313.
- McCubbin, H. J., & Patterson, J. M. (1983). The family stress process: The Double ABDX Model of adjustment and adaptation. In H. I. McCubbin, M. B. Sussman, & J. M. Patterson (Eds.), *Social stress and the family: Advances and development in family stress theory and research* (pp. 7-21). New York: A. A. Worth.
- McCullough, M. E. (1981). *Parent and sibling definition of situation regarding transgenerational shift in care of a handicapped child*. Unpublished doctoral dissertation, University of Minnesota, Minneapolis.
- McHale, S. M., & Gamble, W. C. (1989). Sibling relationships of children with disabled and nondisabled brothers and sisters. *Developmental Psychology*, 25, 421-429.
- McHale, S. M., & Pawletko, T. M. (1992). Differential treatment of siblings in two family contexts. *Child Development*, 63, 68-81.
- McHale, S. M., Sloan, J., & Simeonsson, R. J. (1986). Sibling relationships of children with autistic, mentally retarded, and brothers and sisters. *Journal of Autism and Developmental Disorders*, 16, 399-413.
- McKinlay, W. W., Brooks, D. N., Bond, M. R., Martinage, D. P., & Marshall, M. M. (1981). The short-term outcome of severe blunt head injury as reported by relatives of the injured persons. *Journal of Neurology, Neurosurgery and Psychiatry*, 44, 527-533.
- McMahon, M. A., Noll, R. B., Michaud, L. J., & Johnson, J. C. (2001). Sibling adjustment to pediatric traumatic brain injury: A case-controlled pilot study. *The Journal of Head Trauma Rehabilitation*, 16(6), 587-593.

- McMillan, T. M., Williams, W. H., & Bryant, R. (2003). Post-traumatic stress disorder and traumatic brain injury: A review of causal mechanisms, assessment, and treatment. *Neuropsychological Rehabilitation*, 13(1-2), 149-164.
- Menke, E. M. (1987). The impact of a child's chronic illness on school-aged siblings. *Children's Health Care*, 15, 132-140.
- Michaud, L. J., Rivara, F. P., Jaffe, K. M., Fay, G., & Dailey, J. L. (1993). Traumatic brain injury as a risk factor for behavioral disorders in children. *Archives of Physical Medicine and Rehabilitation*, 74, 368-375.
- Miles, M. B., & Huberman, A. M. (1984). *Qualitative data analysis: A sourcebook of New Methods*. Beverley Hill, CA: Sage Publications.
- Miles, M. B., & Huberman, A. M. (Eds.) (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Miller, L. (1991). Significant others: Treating brain injury in the family context. *Journal of Cognitive Rehabilitation*, 9, 16-25.
- Mintz, M. C., Van Horn, K. R., & Levine, L. J. (1995). Developmental models of social cognition in assessing the role of family stress in relatives' predictions following traumatic brain injury. *Brain Injury*, 9(2), 173-186.
- Mishler, E. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University.
- Mitchel, E. S. (1986). Multiple triangulation: A methodology for nursing science. *Advances in Nursing Science*, 8, 18-26.
- Montgomery, J., & Fewer, W. (1988). *Family systems and beyond*. New York: Human Sciences Press.
- Morse, J. M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research*. Thousand Oaks: Sage Publications.
- Murray, J. (2001a). Loss as a universal concept: A review of the literature to identify common aspects of loss in diverse situations. *Journal of Loss and Trauma*, 6, 219-241.
- Murray, J. (2001b). *Children and grief: A role for us all*. Unpublished manuscript, The University of Queensland, Brisbane, Australia.
- Murray, J., Farley, R., & Wilson, T. (2002). *Children, adolescents and loss: Participant's booklet*. Unpublished manuscript, The University of Queensland, Brisbane Australia.
- Nash, J., Appleton, R., Rowland, B., Saltmarsh, J., & Sellars, J. (1997). Immediate medical and nursing needs. In R. Appleton & T. Baldwin (Eds.), *Management of Brain Injured Children* (pp. 43-69). Oxford: Oxford University Press.

- National Head Injury Foundation (1985). *Fact sheets: Statement of need, extent of the problem and questions about traumatic brain injury*. South Borough, MA: National Head Injury Foundation.
- National Health and Medical Research Council (NHMRC) (1999). *National statement on ethical conduct in research involving humans*. Retrieved February 1999, from NHMRC Web site:
<http://www.health.gov.au/nhmrc/issues/researchethics.htm>.
- National Institutes of Health (NIH) (1999). *Report of the NIH consensus development conference on the rehabilitation of persons with traumatic brain injury*. Bethesda, MD: U.S. Department of Health and Human Services.
- National Institute of Neurological Disorders and Stroke (1989). *Interagency head injury task force report*. Bethesda, MD: National Institute of Health.
- Newsome, R., & Kendall, E. (1996). Expansion rehabilitation: An empowering conceptual framework for rehabilitation following acquired disability. *The Australian Journal of Rehabilitation Counselling*, 2(2), 71-85.
- Noh, S., Dumas, J. E., Wolf, L. D., & Fisman, S. N. (1989). Delineating sources of stress in parents of exceptional children. *Family Relations*, 38, 456-461.
- Orsillo, S. M., McCaffrey, R. J., & Fisher, J. M. (1993). Siblings of head-injured individuals: A population at risk. *Journal of Head Trauma Rehabilitation*, 8(1), 102-115.
- Owensworth, T. L., & Oei, T. P. (1998). Depression after traumatic brain injury: Conceptualisation and treatment considerations. *Brain Injury*, 12, 735-751.
- Packman, W. L., Crittenden, M. R., Schaeffer, E., Bongar, B., Rieger Fischer, J. B., & Cowan, M. J. (1997). Psychosocial consequences of bone marrow transplantation in donor and nondonor siblings. *Journal of Developmental and Behavioral Pediatrics*, 18, 244-253.
- Parkes, C. M. (1971). Psychosocial transitions: A field for study. *Social Science and Medicine*, 5, 101-115.
- Parkes, C. M. (1975). What becomes of redundant world models? A contribution to the study of adaptation to change. *British Journal of Medical Psychology*, 48, 131-137.
- Parkes, C. M. (1988). Bereavement as a psychosocial transition: Processes of adaptation to change. *Journal of Social Issues*, 44, 53-65.
- Patton, M. Q. (1987). *How to use Qualitative Methods in Evaluation*. Newbury Park: Sage Publications.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. London: Sage Publications Ltd.

- Peretti, P. O., & Abderholden, P. (1995). Effect of imputed or implied loss of parental affection due to the brain-damaged child in the family on sibling rivalry. *Indian Journal of Clinical Psychology*, 22(2), 23-26.
- Perlesz, A., Kinsella, G., & Crowe, S. (1999). Impact of traumatic brain injury on the family: A critical review. *Rehabilitation Psychology*, 44(1), 6-35.
- Perlesz, A., Kinsella, G., & Crowe, S.F. (2000). Psychological distress and family satisfaction following traumatic brain injury: Injured individuals and their primary, secondary and tertiary carers. *Journal of Head Trauma Rehabilitation*, 15(3), 909-929.
- Perrott, S.V., Taylor, H.G., & Montes, J.L. (1991). Neurological sequelae, familial stress, and environmental adaptation following pediatric head injury. *Developmental Neuropsychology*, 7, 69-86.
- Peters, L. C., Stambrook, M., Moore, A. D., & Essess, L. (1990). Psychosocial sequelae of closed head injury: effects on the marital relationship. *Brain Injury*, 4(1), 39-47.
- Pinkston, J.B., Santa-Maria, M.P., & Davis, R.D. (2000). Long-term outcome following moderate traumatic brain injury at age 3 months. *Brain and Cognition*, 44 (1), 71-74.
- Polit, D. F., & Hungler, B. P. (1999). Analysis of qualitative data (3rd ed). In *Nursing research: Principles and methods* (pp. 573-590). Philadelphia, PA: Lippincott.
- Porr, S. (1999). Children with traumatic brain injury. In S. Porr & E. Rainville (Eds.), *Pediatric therapy: A systems approach* (pp. 525-544). Philadelphia: F. A. Davis.
- Powell, R. A., Single, H. M., & Lloyd, K. R. (1996). Focus groups in mental health research: Enhancing the validity of user and provider questionnaires. *International Journal of Social Psychiatry*, 42(3), 193-206.
- Prussia, G. E., Kinicki, A. J., & Bracker, J. S. (1993). Psychological and behavioral consequences of job loss: A covariance structure analysis using Weiner's (1985) attribution model. *Journal of Applied Psychology*, 78(3), 382- 394.
- Punch, K. F. (1998). *Introduction to social research: Quantitative & qualitative approaches*. London: Sage Publications Ltd.
- Rennie, D. L., Phillips, J. R., & Quataro, G. K. (1995). Grounded theory: A promising approach to conceptualisation in psychology? In B. G. Glaser (Ed.), *Grounded theory: 1984-1994* (pp. 141-162). Mill Valley, CA: Sociology Press.
- Resnick, C. (1993). The effect of head injury on family and marital stability. *Social Work in Healthcare*, 18, 49-62.

- Rich, M., & Ginsburg, K. R. (1999). The reason and rhyme of qualitative research: why, when, and how to use qualitative methods in the study of adolescent health. *Journal of Adolescent Health, 25*, 371-378.
- Rivara, J. B. (1994). Family functioning following paediatric traumatic brain injury. *Paediatric Annals, 23*, 38-43.
- Rivara, J. B., Fay, G. C., Jaffe, K. M., Polissar, N., Shurtleff, H., & Martin, K. (1992). Predictors of family functioning one year following traumatic brain injury in children. *Archives of Physical Medicine and Rehabilitation, 73*, 899-910.
- Rivara, J. B., Jaffe, K. M., Polissar, N. L., Fay, G.C., Liao, S., & Martin, K.M. (1996). Predictors of family functioning and change 3 years after traumatic brain injury in children. *Archives of Physical Medicine and Rehabilitation, 77*, 754-764.
- Rose, J., & Jevne, R. F. (1995). Psychosocial processes associated with athletic injuries. In B. G. Glaser (Ed.), *Grounded theory 1984-1994* (pp. 423-443). Mill Valley, CA: Sociology Press.
- Roth, E.R. (2001). The assessment of motor deficits following pediatric brain injury. In V.H. Booney & A. Pumariaga (Eds.), *Clinical Assessment of Child and Adolescent Behavior* (pp. 119-136). New York, NY: John Wiley & Sons, Inc.
- Royal, C. D., Headings, V. E., Molnar, E. T., & Ampy, F. R. (1995). Resilience in siblings of children with sickle cell disease. *Journal of Genetic Counseling, 4*(3), 199-217.
- Rutter, M. (1981). Psychological sequelae of brain damage in children. *American Journal of Psychiatry, 138*, 1533-1544.
- Ryde-Brandt, R. (1992). *Distress, defence, and support: Reactions in mothers of children with different disabilities*. Lund: University of Lund.
- Sahler, O., & Carpenter, P. (1987). Developmental differences among siblings' perceptions of the pediatric cancer experience. *Journal of Developmental and Behavioural Pediatrics, 8*, 121.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 83*, 27-37.
- Sargent, J., Sahler, O. J., Roghmann, K., Mulhern, R., Barbarin, O., Carpenter, P., et al. (1995). Sibling adaptation to childhood cancer collaborative research study: Siblings' perceptions of the cancer experience. *Journal of Pediatric Psychology, 20*(2), 151-164.
- Savage, R. C., & Wolcott, G. F. (Eds.) (1994). *Educational dimensions of acquired brain injury*. Texas: PRO-ED.

- Scarr, S., & Gracek, S. (1982). Similarities and differences among siblings. In M. E. Lamb & B. Sutton Smith (Eds.), *Sibling relationships: Their nature and significance across the lifespan*. Hillsdale, NJ: Earlbaum.
- Seligman, M., & Darling, R. B. (1997). *Ordinary families, special children*, (Rev. ed.). New York: Guilford.
- Serio, C. D., Kreutzer, J. S., & Gervasio, A. H. (1995). Predicting family needs after brain injury: Implications for intervention. *Journal of Head Trauma Rehabilitation*, 10(2), 32-45.
- Sherwin, E. D., & O'Shanick, G. J. (1998). From denial to poster child: Growing past the injury (2nd ed.). In M. Ylvisaker (Ed.), *Traumatic brain injury rehabilitation: Children and adolescents* (pp. 331-343). Newton, MA: Butterworth-Heinemann.
- Shmerling, A., Schattner, P., & Piterman, L. (1993). Qualitative research in medical practice. *Medical Journal Australia*, 158, 619-21.
- Singer, G. H. S. (1996). Constructing supports: Helping families of children with acquired brain injury. In G. H. S. Singer, A. Glang, & J. M. Williams (Eds.), *Children with acquired brain injury: Educating and supporting families* (pp. 1-22). Baltimore: Paul. H. Brookes Publishing.Co.
- Snow, J. H., & Hooper, S. R. (1994). *Pediatric traumatic brain injury: Developmental clinical psychology and psychiatry: Vol. 31*. Thousand Oaks, CA: Sage Publications.
- Sokol, D. K., Ferguson, C. F., Pitcher, G. A., Huster, G. A., Fitzhugh-Bell, K., & Luerssen, T. G. (1996). Behavioural adjustment and parental stress associated with closed head injury in children. *Brain Injury*, 10(6), 439-451.
- Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 134-142.
- Strauss, A., (1959) *Mirrors and Masks: The Search for Identity*. Glencoe, IL: Free Press.
- Strauss, A. (Ed.). (1984). *When medicine fails* (4th ed.). New Brunswick: Transaction Books.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage Publications.
- Swanson-Kauffman, K.M. (1986). A combined qualitative methodology for nursing research. *Advances in Nursing Science*, 8(3), 58-69.

- Taylor, S. C. (1980). The effects of chronic childhood illnesses upon well siblings. *Maternal-Child Nursing Journal*, 6, 109-116.
- Taylor, H. G., Drotar, D., Wade, S., Yeates, K., Stancin, T., & Klein, S. (1995). Recovery from traumatic brain injury in children: The importance of the family. In S. H. Broman & M. E. Michel (Eds.), *Traumatic Head Injury in Children* (pp. 188-216). New York, NY: Oxford University Press.
- Taylor, H. G., Yeates, K. O., Wade, S. L., Drotar, D., Stancin, T., & Minich, N. (2002). A prospective study of short- and long-term outcomes after traumatic brain injury in children: Behavior and achievement. *Neuropsychology*, 16(1), 15-27.
- Teel, C. S. (1991). Chronic sorrow: Analysis of a concept. *Journal of Advanced Nursing*, 16, 1311-1319.
- Tew, T., & Laurence, K. M. (1973). Mothers, brothers and sisters of patients with spina bifida. *Developmental Medicine and Child Neurology*, 15(Suppl. 29), 69-76.
- Thomsen, I. V. (1984). Late outcome of very severe blunt head trauma: A 10-15 year second follow-up. *Journal of Neurology, Neurosurgery and Psychiatry*, 47, 260-268.
- Tritt, S. G., & Esses, L. M. (1988). Psychosocial adaptation of children with chronic medical illnesses. *American Journal of Orthopsychiatry*, 58, 211-220.
- Trolley, B. C. (1993-1994). A bridge between traumatic life events and losses by death. *Omega*, 28, 285-300.
- Unsworth, R., Godfrey, H., Bishara, S. N., & Sanders, M. R. (1998). Behavioural problems following TBI-Multi-method assessment of behavioural problems following traumatic brain injury in childhood. *CABIR, Community Rehabilitation following Acquired Brain Injury*, 2(1), 33-40.
- Van Balen, H. G., Mulder, T., & Keyser, A. (1996). Towards a disability-oriented epidemiology of traumatic brain injury. *Disability and Rehabilitation*, 18(4), 181-90.
- Varghi-Khadem, F., O'Gorham, A. M., & Watter, C. V. (1985). Aphasia and handedness in relation to hemispheric side, age at injury and severity of cerebral lesion during childhood. *Brain*, 108, 677.
- Verger, K., Junque, C., Jurado, M. A., Tresserras, P., Bartumeus, F., Nogues, P., et al. (2000). Age effects on long-term neuropsychological outcome in paediatric traumatic brain injury. *Brain Injury*, 14(6), 495-503.
- Waaland, P. K., & Kreutzer, J. S. (1988). Family response to childhood traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 3(4), 51-63.

- Waaland, P., & Raines, S. (1991). Families coping with childhood neurological disability: Clinical assessment and treatment. *Neurological Rehabilitation, 1*, 19-27.
- Wade, S., Drotar, D., Taylor, H. G., & Stancin, T. (1995). Assessing the effects of traumatic brain injury on family functioning: Conceptual and methodological issues. *Journal of Pediatric Psychology, 20*(6), 737-752.
- Wade, S. L., Taylor, H. G., Drotar, D., Stancin, T., & Yeates, K. O. (1996). Childhood traumatic brain injury: Initial impact on the family. *Journal of Learning Disabilities, 29*(6), 652-661.
- Wade, S., Taylor, H. G., Drotar, D., Stancin, T., & Yeates, K. O. (1997). Childhood traumatic brain injury: Initial impact on the family. In E. D. Bigler, E. Clark, & J. E. Farmer (Eds.), *Childhood traumatic brain injury: Diagnosis, assessment and intervention* (pp. 115-131). Austin, Texas: PROED.
- Wade, S. L., Taylor, H. G., Drotar, D., Stancin, T., & Yeates, K. O. (1998). Family burden and adaptation during the initial year after traumatic brain injury in children. *Pediatrics, 102*(1), 110-117.
- Wade, S. L., Taylor, H. G., Drotar, D., Stancin, T., & Yeates, K. O. (2002). A prospective study of long-term caregiver and family adaptation following brain injury in children. *The Journal of Head Trauma Rehabilitation, 17*(2), 96.
- Walker, C. L. (1988). Stress and coping in siblings of childhood cancer patients. *Nursing Research, 37*, 208-212.
- Ward, J. D. (1995). Pediatric issues in head trauma. *New Horizons, 3*, 539-45.
- Watts, R., & de L Horne, D. J. (Eds.). (1994). *Coping with trauma: The victim and the helper*. Queensland, Australia: Australian Academic Press.
- Weber, R. P. (1990). *Basic content analysis* (2nd ed.). Newbury Park, California: Sage.
- Whitchurch, G. G., & Constantine, L. L. (1993). Systems theory. In P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), *Sourcebook of family theories and methods: A contextual approach* (pp. 325-352). New York: Plenum Press.
- Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent versus professional depiction of the adjustment of mentally retarded children. *American Journal of Orthopsychiatry, 51*, 63-70.
- Willer, B., Allen, K., Durnan, M., & Ferry, A. (1990). Problems and coping strategies of mothers, siblings and young adult males with traumatic brain injury. *Canadian Journal of Rehabilitation, 3*(3), 167-173.

- Williams, J.M. (1991). Family reaction to head injury. In J.M. Williams & T. Kay (Eds.), *Head Injury: A Family Matter* (pp. 81-99). Baltimore: Paul H Brookes Publishing Co.
- Williams, P. D. (1997). Siblings and pediatric chronic illness: A review of the literature. *International Journal of Nursing Studies*, 34(4), 312-323.
- Williams, P. D., Lorenzo, F. D., & Borja, M. (1993). Pediatric chronic illness: Effects on siblings and mothers. *Maternal-Child Nursing Journal*, 21(4), 111-121.
- Willoughby, J., & Keating, N. (1995). Being in control: The process of caring for a relative with Alzheimer's Disease. In B. G. Glaser (Ed.), *Grounded theory 1984-1994* (pp. 281-300). Mill Valley, California: Sociology Press(2).
- Wilson, K., Roe, B., & Wright, L. (1998). Telephone or face-to-face interviews? A decision made on the basis of a pilot study. *International Journal of Nursing Studies*, 35, 314-321.
- Winkler, P. (1995). Head injury (3rd ed.). In E. Umphred, (Ed.), *Neurological rehabilitation* (pp. 421-453). St Louis, MO: Mosby.
- Yeates, K. O. (2000). Closed-head injury. In K. O. Yeates, M. D. Ris, & H. G. Taylor (Eds.), *Pediatric neuropsychology: Research, theory, and practice* (pp. 92-116). New York: Guilford.
- Yee, B. (2001). *Enhancing security: A grounded theory of Chinese survival in New Zealand*. Unpublished PhD Dissertation, University of Canterbury.
- Ylvisaker, M. (1998). *Traumatic brain injury rehabilitation: Children and Adolescents* (2nd Ed.). Boston, MA: Butterworth-Heinemann.
- Ylvisaker, M., & Szekeres, S. F. (1998). A framework for cognitive rehabilitation (2nd Ed.). In M. Ylvisaker (Ed.), *Traumatic Brain Injury Rehabilitation: Children and Adolescents*. Boston, MA: Butterworth-Heinemann.
- Zeltzer, L. K., Dolgin, M. J., Sahler, O. J., Roghmann, A., Barbarin, O. A., Carpenter, P. J., et al. (1996). Sibling adaptation to childhood cancer collaborative study: Health outcomes of siblings of children with cancer. *Medical and Pediatric Oncology*, 27, 98-107.