FOREVER DIFFERENT: SIBLINGS' EXPERIENCES OF LIVING WITH A BROTHER OR SISTER WHO HAS A TRAUMATIC BRAIN INJURY

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science
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Abstract

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Studies of parents who have a child with a brain injury suggested that living with a person who has a brain injury can be a difficult experience. Few studies, however, have described the experience of living with a sibling who has a brain injury. This qualitative exploratory study was undertaken to examine the experiences of siblings living with a brother or sister who had a traumatic brain injury. Eight siblings between the ages of 14 and 30 years were interviewed. The verbatim interview data were analyzed revealing several themes. The overarching theme was that well siblings’ lives were forever different after their siblings’ injuries. Their lives were different than they had been, different than they had expected them to be, different than those of their friends, and continually changing. The overarching theme was supported by four themes. Well siblings described the Change in Sibling as the impetus for change and Mixed Emotions as their reactions to their experiences. Different Life Rhythm highlighted changes in the way they went about day-to-day life, while Change in Self acknowledged how they were different as people. The results of the study have implications for Family Systems Theory, research and the type of care rehabilitation providers give to siblings.
Acknowledgments

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Chapter 1: Introduction

Background

Brain injuries, or head injuries as they are often labelled, are one of the leading causes of mortality and prolonged morbidity in young people (Brazil, 1992; Jacobs, 1988; Wong, Dornan, Schentag, Ip, & Keating, 1993). Brain injuries can be present at birth or can be acquired later in life. Acquired brain injuries can result from problems such as brain tumors, meningitis, anoxia secondary to cardiac arrest or trauma. Traumatic brain injuries (TBIs) are those brain injuries which result from mechanical force or contusion of the brain (Gatens & Herbert, 1996). According to the Ontario Trauma Registry (1995), there were nearly 10,000 people in Ontario who experienced TBIs in 1994, the majority of whom were males in their teens or twenties. Advances in emergency services have allowed people with severe TBIs to survive (Brazil, 1992; Cope & O'Lear, 1993). Also, the shift from institutional to community-based care has resulted in people with TBIs being rehabilitated at home (Cope & O'Lear, 1993). Eighty percent of people with brain injuries eventually return home to live with a family member from whom they receive continued rehabilitation and care (Florian, Katz, & Lahav, 1989; Kreutzer, Marwitz, & Kepler, 1992).

When a young person who has a TBI returns home, he or she often lives with other siblings who are well. This researcher's clinical observations indicated that the lives of the well siblings could be profoundly affected by the presence of the injured sibling. Also, the literature concerning the effects of living with an injured sibling which is based on anecdotal data from siblings (Kasowski, 1994; Maurer, 1991; O'Hara et al., 1991; Spanbock,
1992) or studies of parents' experiences, has suggested that siblings experience frustration, anger, and resentment, which supported the observations of this researcher.

The literature on the experiences of families with a family member who has a brain injury had been reviewed by Livingston and Brooks (1988), Florian et al. (1989), Brooks (1991), Kreutzer et al. (1992), Rivara (1994), and Wade, Drotar, Taylor and Stancin (1995). The conclusions were: (a) brain injuries have a long-term negative impact on family functioning; (b) family members often have clinically significant levels of psychological distress, anxiety, and depression after the injury; and (c) these levels increase with time. This information primarily related to the experiences of parents and spouses of people with brain injuries. The experiences of well siblings have not been studied, but siblings are part of the family and thus their experiences may be similar.

Furthermore, the above researchers reported that family disturbance and burden were related to the emotional and personality disturbances of the person with the brain injury, not the physical limitations. Emotional and personality changes are common after brain injuries and include such things as emotional instability and obsessive traits. Other problems that individuals with brain injuries experience often include confusion, lack of initiation, decreased attention span, impaired judgment, poor problem-solving skills, impulsiveness, agitation and lack of insight (Gatens & Hebert, 1996). It is also known from the literature on children of parents with mental illness that children often do not understand cognitive and psychological changes and have difficulty adjusting to them (McLaughlin, 1992; Stambrook, Moore, Gill, & Peters, 1994). Thus, well siblings might
have difficulty adjusting to living with a brother or sister who has a TBI because of the nature of the injury.

As a rehabilitation nurse working in the community this researcher saw many young people with brain injuries living at home. The long-term rehabilitation and care of the young person with the brain injury involves the whole family. However, the rehabilitative care provided by health care professionals is usually focused on the person who has the brain injury and his/her parents. Well siblings receive little direct care or support in the rehabilitation process—an observation that was supported by the anecdotal reports of well siblings (Maurer, 1991; O'Hara et al., 1991; Spanbock, 1992).

**Problem Statement**

The care of young persons with TBIs had been reported to negatively affect parents, and was suspected to negatively affect well siblings. However, there was limited scientific knowledge about what well siblings actually experience. Also, well siblings are likely to be support persons for the injured sibling for a long time, yet they are often excluded from the rehabilitation process. This study examined well siblings' experiences of living with a brother or sister who has a TBI. It was hoped that the knowledge gained would provide initial insights into the experiences of well siblings which could facilitate the integration of well siblings into the rehabilitation process.
**Literature Review**

Following is a review of the research related to the experiences of siblings living with a brother or sister who has a TBI. Using computerized databases for nursing, medicine, and psychology, few studies were found which provided insights from siblings who were living with a brother or sister who had a brain injury. Thus, the literature review was expanded to include studies of any family member of a person who had a brain injury or siblings living with a brother or sister who had a chronic illness. It was believed that the studies of family members of persons with brain injuries would describe the experience of living with someone with a brain injury, albeit not from a sibling perspective. Similarly, it was believed that the studies of siblings living with a brother or sister who had a chronic illness would provide sibling insights into what it is like living with someone who has a chronic disability. It was recognized that the sequelae of brain injuries and chronic illnesses may be similar. Studies were excluded if they addressed only the immediate effect of a brain injury on the family or focused on the marital relationship. Similarly, studies in which the chronic illness of the children studied was congenital or terminal were excluded because of the dissimilar nature of the disability to brain injury. In the reports that were reviewed, several headings were frequently noted and this literature review was organized accordingly. The headings were (a) family life experiences, (b) sibling relationship experiences, (c) social experiences, and (d) emotional experiences.
Family Life Experiences

The first area of literature reviewed was how siblings and parents living with a child who has a TBI or chronic illness experience family life. The anecdotal reports of both well siblings (O'Hara et al., 1991; Spanbock, 1992) and parents (Lezak, 1978) indicated that parents had less time to spend with well siblings when one child in the family had a TBI. There was a restriction of the free time of all family members and a decrease in family activities. Numerous studies of both well siblings (McHale & Gamble, 1989; Tritt & Esses, 1988; Willer, Allen, Durnan, & Ferry, 1990) and parents (Bergland & Thomas, 1991; Brown & McCormick, 1988; Mauss-Clum & Ryan, 1981; Romano, 1974; Williams, Lorenzo, & Borja, 1993) supported the notion that family time was consumed by the rehabilitation and care of the child who was injured or ill, leaving less time for family activities. Two quantitative studies of family functioning using the Family Assessment Device (FAD) also found that parents and spouses rated their families as more dysfunctional than a control group (Bragg, Klockars, & Berninger, 1992) or normative data (Kreutzer, Gervasio & Camplair, 1994). In contrast, two other studies which also used the FAD found family functioning to be within normal limits as rated by primary caregivers (Hall, Karzmark, Stevens, Englander, O’Hare, & Wright, 1994) and siblings (Orsillo, McCaffrey & Fisher, 1993). Moreover, a qualitative study of well siblings living with a brother or sister who had a chronic illness (Gallo, Breitmayer, Knafl, & Zoeller, 1991) indicated well siblings received no less parental attention after a sibling became ill. These seemingly inconsistent findings are difficult to explain. The findings are inconsistent
within the sibling and the caregiver group, so the findings are not explained simply by perspective. Similarly, the findings are inconsistent regardless of the severity of injury, the length of time since injury, or the type of chronic illness. Furthermore, although the FAD does not capture family time or family activities specifically and thus a normal score on the FAD is not necessarily contradictory to findings of decreased family time or family activities, there is still inconsistency in the findings which cannot be explained.

Within the broader area of family life experiences, many siblings reported having added responsibilities. Anecdotal reports by Maurer (1991), O'Hara et al. (1991) and Spanbock (1992) noted that well siblings were often relied on by parents to help care for their siblings with brain injuries. Siblings felt responsible for constantly encouraging and being there for the injured sibling. Studies of siblings (Gallo et al., 1991; McHale & Gamble, 1989; Tritt & Esses, 1988; Willer et al., 1990) and parents (Williams et al., 1993) supported the idea that well siblings have increased responsibility when living with a child who has a brain injury or chronic illness. In fact, the siblings interviewed by Willer et al. described themselves as assistant parents and identified increased responsibilities as one of the top five problems they were facing as a result of the TBIs of their brothers. Gallo et al. identified specific responsibilities such as reminding the ill child to take medications, watching the ill child, and protecting the ill child. Two studies (McHale & Gamble, 1989; Williams et al., 1993) suggested that the added responsibility was greater if the well sibling was a girl and/or older than the ill sibling. This is consistent with the general literature on sibling relationships (Goetting, 1986).
Thus, the research suggested that well siblings living with a brother or sister who has a brain injury take on added responsibilities within the family, although there were few details about what the added responsibilities are. Also, the sex and age of the well sibling seemed to play a role in determining the responsibilities of the well sibling. Lastly, there were inconsistent findings about the effect of a family member with a brain injury on family functioning.

**Sibling Relationship Experiences**

Concern and involvement are aspects of the sibling relationship which have been investigated with conflicting results. In an anecdotal report by O'Hara et al. (1991), three adult siblings who no longer lived with their injured siblings reported feeling more loyal to and more encouraging of their injured siblings after their injuries. In comparison, parents reported a decrease in sibling involvement and concern over time both anecdotally (Lezak, 1978) and in semi-structured interviews (Rivara, Fay, Jaffe, Polissar, Shurtleff, & Martin, 1992). In two qualitative studies (Johnson, 1995; Willer et al., 1990) in which well siblings, most of whom were in their late teens, were asked to describe their experiences of living with a sibling who had a brain injury, siblings reported feeling more concerned about their siblings since the injuries and saw themselves more as friends. Theoretical literature on normal sibling relationships has suggested that in early adulthood and when children leave home there is less contact between siblings, but they are often more supportive of each other and their relationships become more like friendships (Goetting, 1986; Vandell, Minnett, & Santrock, 1987). Thus, what parents have interpreted as decreased involvement
and siblings have described as becoming more concerned may represent different views of the same events and may be part of what all siblings experience as a natural progression in their relationships.

Conflict in the sibling relationship has also been investigated, and here too there have been conflicting results. The well siblings studied by Johnson (1995) and Willer et al. (1990) reported a decrease in sibling rivalry after the injury of their siblings. In contrast, Bergland and Thomas (1991) and Rivara et al. (1992) studied parents of children with brain injuries who reported there were more conflicts between siblings after the injury. Although the questions asked in these four studies were similar, the samples and methods varied. Johnson used observation and a group interview with siblings. Willer et al. used the nominal group technique with siblings. Bergland and Thomas used a semi-structured interview with individual parents. Rivara et al. used a semi-structured interview with families. Thus, the difference in methods may explain the different results, as might the perspective of the individuals providing the information, namely, siblings versus parents. Another explanation may lie in the age of the siblings. The siblings who reported decreased conflict tended to be primarily teenagers and young adults (Johnson, 1995; Willer et al., 1990), whereas the siblings amongst whom parents reported increased conflict were younger (Bergland & Thomas, 1991; Rivara et al., 1992). As was noted above, sibling relationships become more supportive as siblings enter adulthood and less conflict would be expected.
There was the suggestion that the concern and conflict between siblings after one has a TBI is not different from that between normal siblings. Concern increases and conflict decreases as the siblings enter adulthood. However, this notion was based on a small number of studies with different designs which made them difficult to compare and thus, although the suggestion makes sense theoretically, it should be interpreted with caution.

Social Experiences

Another area which has been explored in the literature is that of the social experiences of siblings and families who live with a child who has a TBI or chronic illness. Several anecdotal reports of siblings living with a brother or sister with a TBI (Hardgrove, 1991; Lezak, 1988; O'Hara et al., 1991; Spanbock, 1992) gave insight into their social experiences. Siblings described how they were no longer normal children and their social activities had decreased. The decrease was related to less free time because of increased family responsibilities, less parental attention, and embarrassment about their injured sibling. Qualitative studies of parents who have children with either a brain injury or chronic illness (Bergland & Thomas, 1991; Brown & McCormick, 1988; Mauss-Clum & Ryan, 1981; Romano, 1974; Williams et al., 1993) supported the anecdotal reports and added that family members tended to invite guests into the home less often as time went on. Friends and extended family slowly decreased involvement with the family of the person with the brain injury. A qualitative study of siblings with siblings who were chronically ill (McHale, Sloan, & Simeonsson, 1986) also reported that well siblings were embarrassed by
their ill siblings. However, the embarrassment was not different from that reported by the healthy control group. Similarly, a quantitative study of siblings with chronically-ill siblings (Daniels, Miller, Billings, & Moos, 1986) found well siblings rated their social activities as no less than healthy controls. The contradictory findings in these last two studies may be explained by the different population—siblings living with children who had chronic illnesses as opposed to brain injuries. However, the reports of parents from these two populations did not differ. Moreover, the Daniels et al. study was the only one that used a tool—the Youth Health and Daily Living Form—to measure the social activities and thus the results are difficult to compare to the anecdotal and qualitative studies.

The anecdotal reports of siblings with brothers or sisters who have brain injuries and the qualitative reports of parents who have children with brain injuries or chronic illnesses suggested that well siblings experience a decrease in social activities. However, the qualitative and quantitative reports of siblings with chronically-ill siblings did not concur. This difference may exist because the findings from siblings living with children who have chronic illnesses may not be generalizable to those siblings living with brothers or sisters who have brain injuries. The results are equivocal about the social experiences of well siblings who live with siblings who have brain injuries.

Emotional Experiences

There were several emotional experiences reported in the literature that was reviewed, the first of which was worry. Anecdotal reports of siblings (O'Hara et al., 1991; Spanbock, 1992) described how siblings worried about the injured person's well-being, the
family's financial survival, and the long-term care of the injured person. This point was supported by qualitative studies of well siblings (Gallo et al., 1991; Willer et al., 1990) who worried about family finances, the death of their parents, the sadness of the ill sibling, and being teased. A qualitative study of parents (Mauss-Clum & Ryan, 1981) found they worried about their finances and the possibility of their child dying or having seizures.

Anecdotal reports of siblings (Kasowski, 1994; Lezak, 1988; Maurer, 1991; O'Hara, 1991) described how they felt angry, frustrated, resentful, and subsequently guilty because of the injury and the added responsibilities they had to assume. Parents reported similar feelings anecdotally (Lezak, 1978). Several qualitative studies of parents with children who had brain injuries (Bergland & Thomas, 1991; Brown & McCormick, 1988; Mauss-Clum & Ryan, 1981; Panting & Merry, 1972; Romano, 1974; Thomsen, 1974) concurred that parents felt frustrated and resentful as well as angry and depressed.

Numerous studies have attempted to quantify the anxiety, distress, and depression experienced by siblings and parents. Orsillo et al. (1993) used the Brief Symptom Inventory to measure distress in siblings who had a brother or sister with a TBI. They reported 83% of the siblings had clinically significant levels of distress. Using the same scale, Kreutzer, Gervasio, et al. (1994) studied parents who had children with TBIs and found only 47% of them had clinically significant levels of distress. Thus, it may seem that siblings experience greater distress than parents. However, the difference may be accounted for by differences between the samples. The injured people in the Orsillo et al. study had been injured at the average age of 16, whereas the injured people in the Kreutzer,
Gervasio et al. study had been injured at the average age of 30. Similarly, there was a large difference in the length of time since injury between the two studies, with the average being 46 months in the Orsillo et al. study and only 8.4 months in the Kreutzer, Gervasio et al. study. Livingston, Brooks, and Bond (1985) used the Leeds Anxiety and Leeds Depression Scales to study female caregivers of men with TBIs. They found 37% and 25% of the sample had levels of anxiety and depression respectively that were above the population norm. Oddy, Humphrey, and Uttley (1978) used the Wakefield Depression Scale to study the female caregivers of people with brain injuries. They considered 24% of the subjects to be at risk for clinical depression as measured by the Wakefield tool. Both Livingston et al. and Oddy et al. found the levels of depression increased from six to twelve months after the injury, but the differences were not statistically significant. In contrast, a study of primary caregivers by Hall et al. (1994) found that stress significantly decreased between the first and second year after the brain injury.

Anecdotal reports of siblings (Maurer, 1991; O'Hara et al., 1991; Spanbock, 1992) described the feelings of pressure and responsibility that well siblings experienced. The anecdotal reports of parents (Lezak, 1978) outlined how they felt trapped and isolated while caring for their injured child or spouse. Two qualitative studies of parents with children who had brain injuries (Brown & McCormick, 1988; Mauss-Clum & Ryan, 1981) described how they felt responsible for the care and quality of life of their injured children.

Lastly, various other emotional experiences have been reported by siblings and parents of those with TBIs. Anecdotal reports of siblings (Maurer, 1991; O'Hara et al.,
1991) described the experience of having a sibling with a TBI as a maturing, transformative process that enriched and strengthened them, while making them more reserved and analytical. Siblings reported experiencing a change in life perspective; they became aware of mortality and appreciative of life. Maurer described the experience of being with her brother who was injured as remarkable, like witnessing a resurrection. Qualitative studies of both siblings (Johnson, 1995; Willer et al., 1990) and parents (Mauss-Clum & Ryan, 1981) suggested similar changes in family members such as feeling more independent and becoming more assertive.

Thus, there was the suggestion that the well siblings of those with TBIs experience worry, anger, frustration, resentment, and guilt. There was some evidence that they experience distress and an indication that it may be greater than that experienced by parents. However, it may be that distress increases over time for all family members or that having younger people with brain injuries is more distressing than having older family members with brain injuries. There was also some evidence that parents experience anxiety and depression, but these emotions have not been studied in well siblings. Siblings may experience similar emotions because they too live with the person who has the brain injury and are often involved in the care of the injured person. Furthermore, given the finding that the anxiety and depression parents experience persists over time and the sibling relationship is very long, it may be clinically important to know if siblings experience these emotions. Lastly, there are several emotional experiences such as feeling enriched and transformed that were identified in the literature.
Summary of the Literature and Gaps in the Literature

In a review of the literature, insights into the experiences of siblings living with a brother or sister who has a brain injury were gained. Well siblings who had a sibling with a TBI experienced changes in family life which included the addition of personal responsibilities. The findings about family functioning after one member has a brain injury were equivocal. There was the suggestion from the research and the theoretical literature that changes in the sibling relationship after the brain injury of a sibling, to some extent, reflected normal age-related changes. That is, concern and conflict were experienced between the injured and the well siblings as they were between normal siblings. The findings about the social experiences of well siblings living with siblings who had brain injuries were equivocal. The literature also suggested that siblings experience many emotions after the TBI of a brother or sister including worry, anger, frustration, distress, enrichment, and independence.

The literature that was reviewed also contained many gaps. There was a lack of specific information about the added responsibilities siblings assume. There was no information about the sibling relationship other than the issues of concern and conflict. It was uncertain if there were changes in the social experiences of siblings after the brain injury of a brother or sister. There were many emotional experiences that were not explored in detail. Therefore, there is still much to be learned about what well siblings experience when living with a brother or sister who has a TBI. Furthermore, the often
inconsistent findings between siblings and parents highlighted the need to examine siblings' experiences from the sibling perspective.

**Conceptual Framework**

Family Systems Theory is often utilized in rehabilitation practice and was used to guide this study. According to Maitz and Sachs (1995), rehabilitation professionals often use Family Systems Theory because they see the brain injury of one member affecting the other members of a family and this theory helps them to understand and address those effects. Systems Theory seeks to explain the behaviour of complex systems such as families (Whitchurch & Constantine, 1993). A system is defined as a "set of elements standing in interrelation among themselves and with the environment" (Whitchurch & Constantine, 1993, p. 326). There are several basic concepts and assumptions that are central to Family Systems Theory which are outlined below with an explanation of how each related to this study.

The most fundamental concept of Family Systems Theory is that a system is characterized by interdependence and mutual influence. The individuals that make up a family system are viewed as connected and thus change in one member of the family affects every other family member (Kay & Cavallo, 1994; Leaf, 1993; Maitz & Sachs, 1995; Whitchurch & Constantine, 1993). Interdependence is closely linked to the concept of feedback loops. When change occurs in a family system, the system attempts to restore harmony through feedback loops. That is, the change in behaviour of one member brings about a series of behaviours in other members which either restores the system to its
original form (homeostasis) or changes the structure of the system (morphogenic) (Whitchurch & Constantine, 1993). In either case, when the change is complete, harmony is restored to the system and the accompanying feelings of anxiety and discomfort are relieved (Friedman, 1981). Thus, the TBI of one family member would be expected to disrupt family life and individual members would be expected to experience changes in behaviour (Maitz & Sachs, 1995). As siblings are members of the family system, they would be expected to experience some changes after a brother or sister has a TBI. However, the experiences of well siblings had not been studied. The focus of this study was to explore the experiences of well siblings living in a family system where one of the siblings had acquired a TBI.

Within the Family Systems Theory, there is also the concept of a hierarchy. This refers to the notion that there are systems within systems and that individuals within systems have different amounts of power and authority (Maitz & Sachs, 1995; Whitchurch & Constantine, 1993). The power and authority within a family is usually centralized in the parental subsystem with decreasing amounts distributed to the children in birth order. The family system is located within the suprasystem of the community and has within it subsystems such as the sibling subsystem, parental subsystem, and marital subsystem. At the time of this study, parental and marital subsystems had been studied extensively, but the sibling subsystem had not. This study was designed to explore that gap by examining the experiences of well siblings who had a brother or sister with a TBI. It was recognized that
the well siblings are only individuals units within the family system and sibling subsystem, and hence could provide only their experiences of those systems.

Another assumption of Family Systems Theory is that individuals are self-reflective (Whitchurch & Constantine, 1993). Human beings have the ability to examine themselves and their systems. In this study, siblings used their self-reflective abilities to examine their behaviours and experiences within the context of larger systems—sibling subsystem, family system and friendship system. The interview questions were worded and ordered such that participants had an opportunity to talk about themselves first and were later prompted to describe their experiences within the sibling subsystem, family system and friendship system.

**Purposes of the Study**

The purpose of the study was to describe siblings' experiences of living with a brother or sister who has a TBI. This information may help health care providers better understand siblings’ experiences. This knowledge may enable health care providers to facilitate the integration of well siblings into the rehabilitation process.
Chapter 2: Method

Research Question

A single research question was asked in this study. It was: From the perspective of well siblings, what are the experiences of living with a brother or sister who has a TBI?

Research Approach

This qualitative study of the experiences of siblings living with a brother or sister who has a TBI used a phenomenological approach. It was phenomenological in the sense that it elicited descriptions of the experiences of individuals (Morse & Field, 1995). It endeavored to provide an accurate description of siblings' experiences of living with a brother or sister who has a TBI. It has been argued that phenomenology must be concerned with the individual's larger social world (Layder, 1994). The individual cannot be examined or understood in isolation. Thus, Family Systems Theory was used in the study to locate the phenomenological description of siblings' experiences within the larger family system and sibling subsystem.

The two assumptions behind phenomenology are that the individual living the phenomenon is able to describe it and that the researcher can come to understand the individual's experience in the process of analyzing it (Morse & Field, 1995). Likewise, Family Systems Theory purports that human beings are self-reflective and thus are able to examine and describe their experiences (Whitchurch & Constantine, 1993).

Data collection using the phenomenological approach took the form of a long interview as described by McCracken (1988). The long interview is a sharply focused,
highly efficient method of inquiry that takes place between the investigator and respondent. It is just one of many possible methods which could have provided the in-depth conversations with individuals that were being sought in this phenomenological study. McCracken's method was chosen because its philosophical tenets are consistent with those of phenomenological inquiry as outlined by Morse and Field (1995). Phenomenology seeks to accurately describe the experience of the phenomenon under study. McCracken describes the long interview as a method that "takes us into the lifeworld of the individual, to see the content and pattern of daily experience. The long interview gives us the opportunity to step into the mind of another person, to see and experience the world as they do themselves" (McCracken, 1988, p. 9). Moreover, McCracken sees the long interview as a method that examines individuals' experiences in order to generate a clear understanding of the experiences of a population. Similarly, the focus of phenomenology is on similar meanings rather than an exact recitation of the individual's experience. Thus, in both phenomenology and McCracken's method, the individual is a primary source of data and individuals' experiences are described with the goal of understanding similar experiences.

**Researcher's Perspective**

According to McCracken (1988) and in the phenomenological approach, the researcher who has experience with the subject matter of her research brings certain thoughts, assumptions, and expectations to the research process. These thoughts must be explored and clearly stated so that the researcher is aware of her beliefs which might bias the data collection and/or analysis. This researcher has clinical nursing experience with
individuals who have TBIs and with their families. This experience suggested that well siblings experience increased family demands and fewer rewards after their siblings are injured. As a result of this, some siblings become attentive, caring, and closer to their injured sibling, while others become resentful and distant. This researcher believes that siblings' responses are often not addressed by health professionals and they may be excluded from the rehabilitation process. As a result of the researcher’s experiences and beliefs, she might have been inclined to conduct this study and interpret the data in a way that supported her own assumptions. In this study the researcher explored the experiences of siblings living with a brother or sister who has a TBI from the sibling’s point of view and attempted to describe those experiences accurately. The researcher took several steps to curtail potential biases which are described in the section entitled Methodological Rigor.

**Sample Size and Sampling**

In this study, in-depth descriptions of siblings' experiences of living a brother or sister who has a TBI were being sought. In order to study siblings' experiences in detail, a small sample of participants was appropriate (Miles & Huberman, 1994; Sandelowski, 1995). Purposive sampling was used to ensure that the participants selected had the experience of interest (Bernard, 1994). A sample of eight participants was sufficient to describe what life is like for well siblings living with a brother or sister who has a TBI (McCracken, 1988; Sandelowski, 1995).
The population of interest included siblings who were living with a brother or sister who had suffered a TBI. The criteria for participants to be included in the study were:

1. The brain injury of the injured sibling must have been of traumatic origin to an otherwise healthy individual. This eliminated the type of injury as a variable in the siblings' experiences.

2. The brain injury of the injured sibling must have no longer been life-threatening. This eliminated the threat of loss and anticipatory grief as factors in the siblings' experiences.

3. The sibling with the brain injury must have been between 13 and 25 years of age. Adolescence and young adulthood are the years when TBI is most likely to occur. Drawing from this population increased the likelihood that the results would be clinically useful.

4. The sibling with the brain injury must have been living at home for at least one year since the injury. Lezak (1986) outlined that family adaptation after a member has a brain injury proceeds in certain stages. When the injured person has been home for about nine months and the injury is no longer life-threatening, the family begins to settle into perceptions and expectations of the injured person that do not change much over the subsequent years. Thus, studying well siblings after the first year of living with a sibling with a brain injury should have ensured that they had the experience of interest and thus enabled them to provide a picture of what life was typically like for them.
5. The well and injured siblings must have been living together with two parents. This ensured that the siblings’ experiences were being studied within the larger family system as had been proposed theoretically. Also, it eliminated single-parent situations as a variable in the siblings' experiences.

The study took place in a large metropolitan area in southern Ontario. An introductory letter about the study (see Appendix A) was sent to several organizations and two organizations agreed to assist in the identification of potential participants. One organization was a Head Injury Association whose membership included individuals with all types of head injuries, their families, and other people with an interest in head injuries. The other organization was a rehabilitation centre that served children, young people, and their families. Approval for the study was obtained from the Office of Research Services, University of Toronto and the Research Ethics Review Committee of the rehabilitation centre.

Staff from the two organizations distributed a letter of introduction about the study (see Appendix B) to potential participants. This was done individually and in groups both directly as in face-to-face meetings and indirectly as an insert in the association newsletter. The letter asked family members to contact the identified staff person at the organization or the researcher if they were interested in knowing more about the study. Eleven family members contacted one of the two organizations and agreed to have their names and phone numbers given to the researcher. The family members included four parents and seven well
siblings. The researcher called the organizations regularly to obtain the names and phone numbers of family members who wanted to hear more about the study. The researcher contacted the family members who volunteered by telephone. The researcher explained the study to the family members using a letter of explanation (see Appendix C). The researcher asked if there was a sibling who may want to participate. If a sibling was identified, the researcher spoke to him/her and explained the study to him/her using the letter of explanation (see Appendix C). If the sibling agreed to participate and met the inclusion criteria, an interview was arranged at a convenient location and time for the participant. Three of the individuals who volunteered did not meet the inclusion criteria (one volunteer was living with the injured sibling, but not their parents; the injured person in one family was under 13 years of age; and one injury was not traumatic in nature).

At the interview, a copy of the letter of explanation (see Appendix C) was given to the sibling. The researcher reviewed the explanation of the study with the sibling and asked the sibling if he/she had any questions. Written consent to participate in the study, including audio-tape recording, was obtained (see Appendix D). A copy of the consent was given to the participant. For the one sibling who was under 16 years of age, the study was also explained to one of his parents and consent was obtained from that parent (see Appendix E). Only after these steps did data collection begin.

**Data Collection Procedures**

The primary data collection strategy was the long interview outlined by McCracken (1988). In this study, the long interview involved one interview with each subject that
lasted approximately one to two hours. One interview took place at the Head Injury Association office, two interviews were conducted at the University of Toronto, and the other five interviews were done in the participants' homes. Steps were taken in order to ensure privacy for the participants such as closing doors and hanging a do not disturb sign. The researcher dressed in a comfortable, yet professional manner to increase the comfort of the participants.

The other form of data collection was a demographic profile which included the age and sex of both the well and injured sibling, as well as the length of time since the injury and the length of time living together since the injury. Readers are referred to Appendix F for the complete demographic profile. The demographic data were gathered at the beginning of the interview, after the consent was obtained, to build trust and to develop a rapport with the participants.

According to McCracken (1988), the long interview is designed to allow respondents to tell their own story in their own words. Each interview began with a general question that McCracken calls a grand-tour question. This question was designed to elicit responses from the subjects that would take the researcher on a tour of the world from the participant's perspective. In this study, the grand-tour question was:

Tell me what it is like living with a brother/sister who has a brain injury?

Throughout the interview the researcher used floating prompts to sustain dialogue and to encourage the participants to elaborate. In this study floating prompts included (a) gestures such as nodding and raising eyebrows to show interest, and (b) repeating one or
more of the participant's key words in a questioning way. Bernard (1994) refers to these as silent and echo probes respectively.

The researcher also used planned prompts. Planned prompts were used only when conversation stemming from the grand-tour question ended and if further information about the phenomenon of interest was desired. Planned prompts took the form of contrast and category questions. Contrast questions are designed to give subjects a point from which to begin discussion of something that has not already been discussed (McCracken, 1988). They gave participants something to compare or contrast in their minds that generated further thinking about their own situations. Category questions refer to categories or relationships that stem from the literature review that the researcher wants to investigate (McCracken, 1988). They were used only after participants had finished responding to the grand-tour and contrast questions to ensure that all areas of interest were discussed during the interview. The complete list of interview questions appears in Appendix F.

The interviews were audio-tape-recorded. That facilitated the flow of the interviews as the researcher did not have to take extensive notes. The researcher made notes of any points that were to be revisited at the end of the interview for further exploration and in case the interview had to be reconstructed afterwards. All of the taped recordings were audible and no reconstruction was necessary.

The researcher concluded each interview by asking the participants if there was anything further they wanted to tell the researcher or any questions they wanted to ask. All participants were given a contact number for the researcher, should they have had any
further questions stemming from the interview. The researcher sought and obtained permission to call all participants should clarification of data have been required. The researcher has had no contact with any of the participants after the interviews.

Two pilot interviews were conducted initially to determine what type of data was generated by the interview questions. No changes to the interview questions were necessary and the data from the two pilot interviews were incorporated into the data analysis.

**Ethical Considerations**

**Informed Consent**

From the steps outlined in the section entitled Sample Size and Sampling, one can see that informed consent was obtained from all participants.

**Risks and Benefits**

As Lezak (1986) outlined, after a sibling who has a brain injury has been home for about nine months, the family settles into a stable existence. Therefore, interviewing siblings after one year should not have posed any serious emotional risk to them or their families. However, participants could have become emotionally upset during or after the interviews. This did not occur during the interviews and no participants have contacted the researcher since the interviews.

Participants were advised that they may not directly benefit from participating in the study. However, they may have benefited from sharing their experiences.
Confidentiality and Anonymity

Participants' rights to privacy and confidentiality were upheld throughout the study process. Steps that were taken to ensure confidentiality included (a) conducting the interviews in a private location, (b) ensuring all records were kept in a secure location, and (c) not identifying participants or family members by name anywhere except on the master list (see Appendix G). Quotations from subjects appear in this and other written reports of the study, but the quotations do not indicate who said them. Thus, participants may be able to identify their own quotations in the reports, but no one else should.

Data Analysis Procedures

McCracken (1988) describes data analysis as a mechanistic and indeterminate path that the researcher must travel to arrive at scholarly assertions from the interview data. The steps of analysis should be outlined in advance with room for flexibility as necessitated by what is discovered. The steps were outlined as a linear process, but are understood to be iterative. In this study, each interview was analyzed as it was completed. Data analysis included the major steps of data organization and data interpretation.

Data Organization

Data organization included the following steps as outlined by Tesch (1990):

1. The researcher completed the post-interview summary (see Appendix F) immediately after the interview. The researcher then listened to the audio-taped interview data to ensure it was audible and complete.
2. The audio-taped interview data were transcribed by a professional typist and entered into the Ethnograph software program.

3. A numbered copy of the transcribed data was printed.

4. The numbered copy was read closely to identify key utterances without concern for their significance. Key utterances were segments of data that provided information about the phenomenon under study and made sense on their own. They did and did not pertain to particular categories from the literature review.

5. Key utterances were marked with a code. A code is a word or symbol that identifies the topic of an utterance. The research question and categories from the literature review were kept close at hand to help with coding, although most of the codes emerged from the data.

6. The reliability of the coded data was ensured through two steps. The researcher randomly choose and recoded three transcripts several days after the original coding. Also, the thesis supervisor coded three transcripts after the researcher had coded them.

7. The codes were revised to provide clarity. The codes were checked for completeness against the research question. The list of codes was revised and all interviews were recoded using the revised list. The final list of codes and a description of the coded topics appears in Appendix H.

Data Interpretation

Data interpretation included the following steps as outlined by McCracken (1988):

1. Within each transcript, the researcher worked with the coded utterances to describe the
meaning or content of the utterances. The researcher examined how the content across utterances was related. The researcher looked for both similarities and contradictions in the data. This led to the identification of content themes within each transcript. The researcher consulted with the thesis supervisor to ensure the interpretations were clear and valid.

2. The researcher then looked for recurrent content themes across transcripts. Explanations for outlying or contradictory themes were sought. Again, the researcher consulted with the thesis supervisor to ensure the interpretations were clear and valid.

3. Interrelationships between the content themes were sought. The researcher used her judgment in determining the overarching theme and major themes. The major themes were supported by sub-themes. A theme was defined as a statement about the experience based on observation of the data (McCracken, 1988).

**Methodological Rigor**

Methodological rigor was promoted by the criteria set out by Sandelowski (1986) for qualitative research, namely, credibility, fittingness, auditability, and confirmability.

**Credibility**

Credibility is the counterpart to internal validity used in quantitative research and refers to the truth value of the findings (Sandelowski, 1986). "A qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own" (Sandelowski, 1986, p. 30). Several steps were
taken in this study to enhance the credibility. First, the researcher declared her perspective so it would be evident that the participants' experiences were being described and not those of the researcher. Second, the interviews took place in a private and relaxed, yet professional environment which should have facilitated the comfort of participants. Third, the interview questions were open-ended and non-directive which encouraged participants to describe their experiences in their own words. Four, both the researcher and the thesis supervisor coded the data to ensure the themes represented the data. Five, the thesis committee reviewed the themes and the supporting data to ensure the themes represented the data.

**Fittingness**

Fittingness is the counterpart to external validity or generalizability used in quantitative studies and refers to the applicability of the findings (Sandelowski, 1986). Fittingness is achieved when the study "findings can fit into contexts outside the study situation, when its audience views its findings as meaningful and applicable in terms of their own experiences," and the descriptions fit the data from which they were derived (Sandelowski, 1986, p. 32). Three steps were taken in this study to enhance the fittingness. First, a review of the literature was conducted which suggested how this study might contribute to the literature and to practice (Hammersley, 1992). Second, demographic data about the sample and details of where the study was conducted were given in the final report which will allow readers to determine if the findings might be applicable to their
situations. Third, the participants were drawn from the population in which brain injuries statistically occur most often; that is, individuals in their teens and twenties.

**Auditability**

Auditability is the counterpart to reliability used in quantitative studies and refers to the consistency of the data (Sandelowski, 1986). Auditability is achieved when another researcher can clearly follow the decision trail of the researcher and arrive at comparable conclusions given the same data, perspective, and situation. In order to enhance the auditability of this study the steps suggested by Sandelowski were followed. These steps included full description of (a) how the researcher became interested in the subject matter, (b) how the researcher viewed the thing studied, (c) the specific purposes of the study, (d) how participants came to be included in the study, (e) how the data were collected, (f) how the data were reduced or transformed for analysis, interpretation, and presentation, (g) the inclusiveness and exclusiveness of the categories developed, and (h) the techniques used to determine the truth value and applicability of the data. A research journal was also kept which included a record of the research process, the impressions of the researcher, and any problems that were encountered and how they were resolved. All research materials will be kept for seven years and will be available for review as required.

**Confirmability**

Confirmability is the counterpart to objectivity used in quantitative research and refers to the neutrality of the research process and product (Sandelowski, 1986). Confirmability is achieved if the study findings are meaningful and were gained by the
researcher engaging with the participants. Miles and Huberman (1994) outlined several steps to avoid biases resulting from the researcher's effect on the research and the effect of the research process on the researcher. Two steps were taken to reduce the effect of the researcher on the research. First, the data collection took place in a location of the participant's choice. Second, the researcher made her intentions and plans clear through the use of letters and verbal explanations. Several steps were also taken to reduce the effect of the research process on the researcher. First, the interviews were spread out over time thus allowing the researcher to withdraw from the situation temporarily. Second, the researcher thought conceptually about the interview data by putting personal thoughts into more theoretical ideas in the post-interview summary (see Appendix F). Third, the researcher used a predetermined interview guide and data analysis plan which kept the research process focused. Four, the conclusions of the study were supported by examples from the data.
Chapter 3: Results

Characteristics of the Participants

Eight people participated in the study; each was living at home with two parents and either a brother or sister who had a traumatic brain injury. Three females and five males were interviewed, all from different families. The participants ranged in age from 14 to 30 years; four were younger than their injured siblings and four were older. Five of the eight participants were the sibling closest in age to the brother or sister with the injury. Six of the eight families had more than two children (two families had three children; three families had four children; and one family had five children). All of the families lived in a large metropolitan area in southern Ontario. The participants were recruited through either a Head Injury Association or a rehabilitation centre.

The siblings with the TBIs included one female and seven males. They ranged in age from 15 to 24 years and had been injured between two and 14 years earlier. In all cases, the siblings with the injuries had been living at home at least one year since the injury. The injuries were all traumatic in nature, but were no longer life threatening. They occurred to previously healthy individuals, as the result of motor vehicle accidents, bicycle collisions, and in one case a fall. The severity of the brain injuries sustained by the siblings was not measured directly. However, the well siblings described the abilities and limitations of their injured siblings during the interviews. They recounted details of their injured siblings' participation in school and work which are provided in Table 1 along with the characteristics of the well siblings. Additional functional descriptions of the abilities
### Table 1  Demographics of the Sample

<table>
<thead>
<tr>
<th>Families</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
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<td>male</td>
<td>male</td>
<td>female</td>
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<tr>
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<td>23</td>
<td>17</td>
<td>20</td>
<td>25</td>
<td>14</td>
<td>24</td>
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<tr>
<td>Age at time of injury</td>
<td>27</td>
<td>11</td>
<td>9</td>
<td>14</td>
<td>17</td>
<td>20</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
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<td>grade 10</td>
<td>university degree</td>
<td>grade 12</td>
<td>grade 12</td>
<td>some college</td>
<td>grade 9</td>
<td>university degree</td>
</tr>
<tr>
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<td>male</td>
<td>female</td>
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<td>male</td>
<td>male</td>
</tr>
<tr>
<td>Age at time of study</td>
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<td>3</td>
<td>5.5</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
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<td>1.5</td>
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<td>4</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
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<td>some high school</td>
<td>some high school</td>
<td>some high school</td>
<td>some high school</td>
<td>some public school</td>
<td>some high school</td>
<td>some high school</td>
</tr>
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<td>Currently engaged in</td>
<td>university courses</td>
<td>work</td>
<td>college and work program</td>
<td>volunteer work</td>
<td>college and work</td>
<td>vocational school</td>
<td>entering university</td>
<td>vocational school</td>
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<tr>
<td>Sex and age at time of study</td>
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<td>females, 16</td>
</tr>
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</table>
and impairments of the injured siblings are based on the reports that the well siblings provided during their interviews. All eight siblings had cognitive difficulties in at least one of the following areas: information processing, attention, memory and judgment.

Similarly, the eight siblings had demonstrated unusual behaviours at various times during their recoveries and many of them continued to experience problems with behaviours such as perseveration, aggression, and impulsiveness. One sibling was a wheelchair user and two others had difficulties walking such that their mobility was restricted or they had to use a cane. One sibling required physical assistance with basic activities of daily living such as dressing and eating. One sibling required verbal prompting with the same activities.

**Overview of the Study Findings**

All participants described the experience of living with a brother or sister who has a traumatic brain injury as *Forever Different*. That is, life was different than it had been before, different than they had expected it to be, different than that of their friends, and continually changing. This overarching finding was supported by four themes—*Change in Sibling, Mixed Emotions, Different Life Rhythm* and *Change in Self*. These themes reflected the experiences of all eight siblings who participated in the study.

The theme *Change in Sibling* highlighted how the siblings with the brain injuries were changed by their injuries. It included descriptions of physical, cognitive and behavioural changes. The well siblings described *Change in Sibling* as the impetus for their *Different Life Rhythm* and *Change in Self*.
The theme *Mixed Emotions* acknowledged that well siblings experienced numerous and sometimes conflicting feelings about the changes within themselves and their lives. Well siblings described *Mixed Emotions* as their reactions to their experiences of *Different Life Rhythm* and *Change in Self*.

The theme *Different Life Rhythm* captured how siblings' lives were *Forever Different*. *Life Rhythm* was defined as the way siblings went about their daily lives in interaction with their families and friends. *Different Life Rhythm* was supported by four subthemes—*Doing what it takes*, *Redefining relationships*, *Learning by trial and error*, and *Wanting someone to talk to*. *Doing what it takes* was reflected in all but one of the participants' stories. *Doing what it takes* represented a variety of new behaviours, activities and responsibilities well siblings had to take on in order to maintain the emotional and physical wellness of those around them. *Redefining relationships* meant that after the injury of their brother or sister, well siblings experienced changes in the activities and relationships they shared with their siblings, families, and friends. All eight participants acknowledged *Redefining relationships*. The last two subthemes were *Learning by trial and error* and *Wanting someone to talk to*. They were identified by six and four participants respectively. These two subthemes described two distinct ways siblings coped with the changes they experienced within a *Different Life Rhythm*.

The theme *Change in Self* referred to the changes well siblings experienced within themselves and their way of thinking about life. Within this theme were descriptions of how the siblings were *Forever Different* as people. *Change in Self* was supported by two
subthemes—Change in priorities and New appreciation for life. A Change in priorities was reported by all eight siblings. It included a description of how the siblings’ interests, values, and preferences changed after the injuries of their brothers and sisters. For four of the siblings, this Change in priorities was closely linked to the realization of their own mortality and a sense of wanting to spend their time differently which was captured within the theme New appreciation for life.

The remainder of this section will elaborate the themes identified above. It will begin with descriptions of the overarching theme Forever Different, followed by the themes Change in Sibling and Mixed Emotions. Finally, the themes Different Life Rhythm and Change in Self will be presented at which time the supporting subthemes will be explored in detail. A schematic presentation of the results is found in Figure 1 and a summary of the representativeness of the themes is outlined in Appendix I.
Figure 1. Schematic presentation of the study findings
Elaboration of the Findings

Forever Different

The participants described the experience of living with a brother or sister who has a traumatic brain injury as **Forever Different**. They were hesitant to label their life situations as better or worse; they chose different. One sibling described the effect of his brother’s injury on his own life this way: “I can’t say I think it’s made it worse... in some ways not so good, but I don’t see it making it worse. It’s different. I suppose in some ways it’s made it better... I guess”. (S#2)

Siblings described their lives as different in many ways. The first way in which their lives were different was simply that they were different than they had been before. After the injury of their brother or sister, their lives were changed. There was an initial period of upheaval when the injuries first occurred which all siblings wanted to talk about. However, when asked to focus on their lives after they had lived with the injured siblings, they continued to identify that life was different than it had been. One sibling recalled: “So I left my job. I left my boyfriend. I was living at home again. Everything that I knew was now completely different”. (S#1)

A second way in which siblings’ lives were different was that they were different than they had expected them to be. As siblings described their current life situations, they also referred to the lives they thought they would have had. They described careers, relationships and opportunities that would have been different. As one sibling outlined:
Well I think a lot of the things that I do now that my brother can’t
are things that we would have been doing together if he hadn’t had his
accident. . . . It’s disappointing. . . . It seems selfish to even be talking about
it, but that’s what I’ve gone through . . . wishing, imagining what it would
be like if it had never happened. (S#3)

Siblings also described their lives as being different than the lives of their friends.
They saw their friends as having fewer responsibilities and more opportunities because of
the different relationships they had with their siblings. In the words of one sibling:

I think I would be very, very close with him right now if he did not
have his accident because he’d be just like his friends are and I’ve become
closer with them. So, I see the exact same relationship a friend of mine has
with his older brother who is just like Ryan¹ and I see what it would have
been like . . . so that kind of upsets me. (S#4)

Siblings saw these differences as permanent—**Forever Different**. They also
described other changes which occurred over time and in that way their lives were

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¹ All names used in this study are fictitious in order to protect the confidentiality of the participants and their families.
continually changing or different. Siblings described how their brothers and sisters who were injured could change from moment to moment as in this sibling’s account:

Before his accident he used to be really naughty and then he was so good all of a sudden—much more helpful. He’s probably the nicest person in the house except when he gets into his temper tantrums. It’s just when he gets angry he totally changes . . . it doesn’t seem like him really. (S#8)

Siblings also described how the abilities of their injured siblings changed over time which in turn changed how they had to respond. One participant recalled:

It’s tough, it’s trying . . . it takes a lot of energy. Real issues like running the gas lawnmower. Is he OK to do that? What if he wants to drive the boat? How do we tell him he can’t? Things you don’t think about while you’re in the hospital. And even two years later you’re still learning things . . . learning new things about it. Things are popping up. Problems he had two years ago he doesn’t have now, but he has different ones. And so its always kind of . . . just when you think you’re getting into a groove, everything changes on you. (S#1)
Further description of how the lives of well siblings were *Forever Different* will be provided throughout the remainder of the results section. Well siblings attributed many of their life changes to the changes in their siblings after their injuries. This *Change in Sibling* will be described below and elaborated throughout the results.

**Change in Sibling**

The participants wanted to talk about how their siblings had changed since their injuries. These descriptions were not the focus of the study, but they are relevant to mention because participants perceived that the changes in their injured siblings necessitated many of the changes in themselves and their lives. Well siblings described their injured brothers and sisters in detail including their: physical appearance, physical abilities and limitations, school and employment histories, habits, preferences and much more. However, all of the participants identified the changes in interpersonal skills, cognitive abilities, and unusual behaviours as most significant.

Four siblings identified that their injured brother or sister had problems with interpersonal skills. These problems included such things as being demanding, constantly interrupting, talking endlessly, speaking loudly, and being unable to follow conversation. A few examples of this type of *Change in Sibling* were:

> When there’s a lot of conversations going on . . . if you’re sitting with a bunch of friends . . . you’re talking; stories are flying; witty remarks and stuff like that, my brother couldn’t keep up. It would be hard for him to
get into it. That’s a limitation he has. That definitely affects him and my
relationship with him. (S#3)

Like if he is at a restaurant, he would find reasons to go up and
introduce himself to some stranger and start talking. He is an extremely
forward person; like anything that comes to his mind he says basically
without any judgment if it’s appropriate or not. (S#4)

He’s demanding. Constantly calling someone, especially my
mother. We got an intercom from his room into the kitchen where he can
call because it was getting to the point where all you could hear is him
yelling and it was getting very frustrating. . . . I think he talks loudly
whereas he didn’t before. He doesn’t know his own volume . . . at the
dinner table there might be three conversations going and he wants to get
this thing in so he talks louder than anybody else. (S#6)

All eight participants noted that their siblings who had a brain injury had
impairments in some aspect of their cognitive abilities. These impairments were in the
areas of speed of information processing, attention, memory, judgment, and organizational
abilities. Several examples siblings cited were:
I’d always seen my brother . . . like you’d give him a problem and he’d figure it out, like almost right away. And after the accident, you’d give him a problem and it would take him a while. I had to get used to it. (S#2)

He’s not very organized. He thinks he can do all these things in a minute. . . . When he has assignments to do, he leaves them to the last minute. And I’ll say, like why didn’t you do a little bit each day, at least you could of had some of it done. He’s learning though. (S#7)

He usually forgets things and so if he’s going to be out later than he told us, he might not remember what time he told us and then he won’t always call. But he has a watch and he can program things like that. (S#8)

All eight well siblings also described unusual behaviours that their brothers and sisters had after their brain injuries. These behaviours involved repetition, aggression, and compulsion. Some anecdotes of this type of Change in Sibling that participants gave were:

He started getting really hard on himself, trying to build back his strength; really pushing himself to the point where it was obsessive. It still is with him, this physical fitness; less obsessive but still very compulsive. It
was tough watching him pushing himself and feeling bad about himself and there was nothing we could really say or do. (S#1)

He gets fixated on certain things and something has to be done right now so every day he'll come home and make his lunch. On my machine . . . I'll get home and I'll have seven messages and three or four of them will be from Ryan, just rambling on to me about things I don't really care about but he thinks I should know anyway. So it's kind of annoying. (S#4)

When she gets real upset it's tough just to turn around and walk away cause she . . . she just starts in. One day you'll be joking with her, just making comments about how she's a cripple or something, just joking . . . she'll be laughing; next day she'll have a spell and she'll just be freaking. She'll bring up all these little things that you said and all these little things that you did. She'll start cutting up others around. You got a friend over, she'll just start saying how they're this and they're that. It's hard to refrain; hard to restrain yourself—realize that it's . . . I guess there really isn't too much you can do about her . . . they told us. I find it really difficult. (S#5)

He's very irrational, like he'll scream a lot and he'll tell people that he hates them or whatever and that he doesn't need them and that he can take care
of himself and that he has friends he can go to or whatever . . . and then he'll walk away and we'll have to go and chase him kind of thing but if he's at home then he'll . . . he'll usually just go up to his room and he'll either start crying or he'll just go up to his room and lie down and watch TV or something. (S#8)

These are just a few of the many examples participants gave of how their siblings had changed after their injuries. These and other examples will be used to explain why the participants and their lives were **Forever Different**. Similarly, siblings gave many examples of the *Mixed Emotions* they felt about their experiences. A brief description of *Mixed Emotions* will be given below with further elaboration given throughout the results section.

**Mixed Emotions**

Siblings described a variety of emotions which accompanied their experiences of living with a brother or sister who has a TBI. *Mixed Emotions* is a theme which acknowledged that those emotions were numerous and sometimes conflicting. The feelings they described were their personal reactions to the changes that meant they and their lives would be **Forever Different**. A sample of such emotional turmoil is outlined in the words of this sibling:
So in that way it's a little less tense, but its still difficult and every once in a while I just get really sad . . . he might say something, do something that reminds me of who he was five years ago and its kind of like . . . shit, but that's not going to be anymore which is why it's so sad. You think sometimes oh, why couldn't it have been me? He was like the total golden child, did everything right, and I was the one who screwed up all my life . . . and so sometimes I, especially when he was in the hospital and I didn't know whether he was going to live or die and everything, I had this overwhelming sense of guilt that it wasn't me—it shouldn't have been him. He had so much more of a promising future. It isn't to say I don't—like I feel good about my life and other things, but it was not fair; he was only like twenty-two. And I would say like at first when I was going through it, it was quite an upheaval and there was some sad times for me personally like the loss of my relationship, but right now, right here looking back I'm kind of glad of the choices that I made, that I chose to stay and things have worked out very well. So I don't know . . . all kinds of mixed emotions.

(S#1)

Exemplars of *Mixed Emotions*, such as this one, pervaded the siblings' accounts of their lives. Further discussion of emotional experiences will be woven into the descriptions of the themes—*Different Life Rhythm* and *Change in Self*.
Different Life Rhythm

The theme *Different Life Rhythm* exemplified how siblings’ lives were *Forever* different. *Life Rhythm* was defined as the way siblings went about their daily lives in interaction with their families and friends. Siblings implied that life is usually predictable—rhythmic. When their siblings were initially injured, the participants’ lives were not predictable. They experienced changes at home, work and school which they wanted to describe in detail. When their siblings came home from hospital, their lives were still unpredictable. After the siblings who had the brain injuries were home for about one year, life again had a predictable, rhythmic nature; however, it was different as this example illustrates:

I look back to when it happened . . . so it’s really just turned our lives kind of upside down, but I would say that since about late fall we’ve kind of been getting more back to normal—like not really normal, but we’ve all kind of gotten into a rhythm at home that wasn't there for a long time. I think that our pace has slowed down a little bit. Well, instead of going out a lot and rushing off to this show or that show or going away for the weekend or having people over to dinner . . . not as much of that is happening, not because we've lost friends or we feel unsociable or something, its more because we sort of like relax more and enjoy each other’s company. (S#1)
There were four subthemes which explained *Different Life Rhythm* in further detail. Each of these will be described in turn with supporting data from the participants.

*Doing what it takes.* *Doing what it takes* represented a variety of new behaviours, activities and responsibilities well siblings had to take on in order to maintain the emotional and physical wellness of those around them after their siblings with brain injuries came home to live. It was acknowledged by all participants except number two. *Doing what it takes* involved different behaviours and activities at different times for different reasons. That is, well siblings acknowledged that they had numerous duties or obligations, some of which were different than before and which changed over time. In that way, their responsibilities were *Forever Different.* Whereas fulfilling their obligations took time and hence altered how siblings went about their days, *Doing what it takes* contributed to their *Different Life Rhythm.* These responsibilities included physical and cognitive-emotional types of behaviours, both of which will be described below.

The physical or task-oriented activities well siblings had to perform included primarily household chores. They were things siblings did to help the family function. Participants described having to do laundry, clean up after the cat, help with home repairs and cleaning. These activities were not new for siblings; they had done them before. What was different after their siblings were injured was that some of them had to do more, some of them did less, and some of them did different activities. The accounts from the participants included:
When my dad needs someone to help him to move something heavy, it's always me. . . My brother can help with the little stuff. . . As far as the duties that don't require physical strength, it's really no different. I have duties; my brother has duties. I guess he did most of them when I was away at school. He would usually have more duties than me because my parents give him an allowance. My parents give him all the chores so he can earn more. He doesn't really have any other income. Now, he's working and I'm not so I've picked up more household chores. Just whoever has time. (S#3)

I feel like he's doing no chores and I'm doing everything. I know he can do it. He doesn't need any help. He just doesn't want to. He's stuck in the old generation where women do the cooking. He expects my mom and sister to cook for him. (S#7)

I don't really have specific kinds of things that are mine to do. Just those I impose on myself. I make sure that I communicate with everyone every day . . . Like household duties and stuff like that—I don't worry myself with that as much. I'm just more the type of person that I don't like it when people feel bad or people feel lonely. I'm just very social. (S#8)
The other types of physical activities well siblings had to perform directly involved their sibling with the injury. These were new behaviours that siblings performed begrudgingly because they had to. The siblings described their experiences these ways:

It was ridiculous. He had to be taken to the washroom. He had to be put to bed. He had to be woken up. In the middle of the night . . . it was nuts. Now, I try to limit myself. I take him out. Anything else, I just let him go to my parents. (S#4)

I gotta be her chauffeur now because she’s unable to drive. She lost most of the movement in her left side so she hasn’t been able to get her license. We have to haul her around all the time. (S#5)

Once when my parents were away, something progressed between my brothers and Paul broke a glass. I went bezerk and hit him in the shoulder. It upset me so much I had to remove myself and my brother stuck him in the elevator to cool off. I never hit my brother like that before. It’s the only way that you can get him to snap out of his violent temper. (S#6)

The other category of responsibilities were cognitive-emotional types of behaviours. These were things siblings did to prevent arguments, ensure safety, promote learning, and
enhance the overall well-being of those around them. These were activities that were required because of the *Change in Sibling* that was described earlier. Whereas the injured siblings had difficulty with memory, attention, impulse control, judgment, and interpersonal skills, well siblings often had to monitor their own behaviour and intervene in their siblings’ behaviours. These interventions included such behaviours as talking to a sibling to calm him or her down, helping a sibling with homework, challenging a sibling to think through a problem, warning a sibling not to cross a street, giving words of encouragement or praise, giving verbal disapproval to inappropriate or unsafe behaviours, and many more. The siblings often labelled these types of behaviours as “watching out for”, “being there”, “babysitting”, or “hand holding”. Examples from several of the participants who identified with this responsibility were:

He's constantly checking with them to make sure. He needs a lot of help; he can't live independently right now. So he's constantly asking, like trying to remember his schedule . . . constantly asking and making sure he knows when my parents are going to be around. So I just tell him; try to answer his questions. It's just draining being around him. (S#4)

I have to have fifty eyes, because you're constantly watching out for him. Paul did you look behind you? Look to your right before you go. Slow
down you’re going to hit somebody. He’s just not aware; you have to be aware for him. So that’s kind of tough. (S#6)

We try to encourage him to do his homework, but he gets confused. He gets very confused and frustrated. Someone always has to do homework with him. I don’t do that anymore because I get frustrated helping him. It’s so basic and I get to the point that it’s just like “why can’t you get it?” I think he gives up before he even begins and that’s frustrating too because you always have to have this energy to motivate him. It’s very draining. I’m not as involved in his life as I used to be because I have my own life; however, I live here and I feel the need to contribute. (S#6)

When my parents are desperate, they come to me. He won’t listen to other people, so when he’s gotten into a bad temper . . . like when we were at my cousin’s wedding, he refused to come into the hall. I followed him around and around and around and finally got him to come in like maybe an hour later, but he was still in a bad mood, but . . . I have to work hard at it . . . be sneaky . . . make up stories . . . try to rationalize with him that it’s so important to the family. (S#8)
The only thing is that we worry about him more because we're afraid he might be taken advantage of because he seems so naive sometimes. He's very trusting. Like if he tells us that he's made a new friend, then we'll always make a point to try to meet this person and see what they are like . . . because . . . just to make sure that the person has good intentions toward him or whatever. And I know my parents don't really do that in my case. (S#8)

As the above examples illustrated, Doing what it takes involved many varied responsibilities. Some of the responsibilities were imposed by parents, some by the siblings themselves, and some were reflexive reactions performed to avert danger (in changing situations). The injured siblings were Forever Different and so were the responsibilities of the well siblings. As their responsibilities changed, their daily lives were altered. In that way, Doing what it takes contributed to a Different Life Rhythm.

As the above examples also illustrated, the well siblings experienced many emotions with respect to their responsibility of Doing what it takes. Siblings found the level of awareness required could be tiring, yet they could feel elated when they noticed small improvements in their siblings' abilities. They saw themselves as having had an impact on their siblings' recoveries. They also described how they got frustrated and exhausted to the point it made them say and do things they later regretted. They also talked about times they did control themselves when they really wanted to retaliate and how they knew they had done the right thing, but felt angry. They were angry because they had to control themselves—be
the bigger ones—yet their injured siblings said and did things that were mean. They had difficulty accepting that those acts were uncontrollable because they seemed purposeful, spiteful. Despite these Mixed Emotions, the siblings still reported a sense of obligation to the injured sibling and their families. They felt committed to their families and a need to do whatever was necessary to keep the family going. They worried about the financial and physical well-being of their siblings and felt they would likely worry for a long time. Two of the female participants knew they were going to be the legal guardians for their injured siblings when their parents were no longer able to perform that function. This left them feeling somewhat burdened but assured that their siblings would be looked after.

Redefining relationships. The second subtheme within Different Life Rhythm was Redefining relationships. It meant that siblings experienced changes in their relationships with their family members and friends after the injuries of their brothers and sisters. All eight participants identified that they had changes in their relationships. They noted that when their siblings were first injured most social and recreational activities ceased for themselves and their families. After their brothers and sister with the brain injuries had been home for about a year, they began to resume those activities, but they were different than before. Their relationships were Forever Different. Whereas relationships and the activities shared therein are a part of everyday life, Redefining relationships contributed to a Different Life Rhythm.

Well siblings described two types of changes in their relationships with their siblings. They talked about changes in their roles and the overall closeness they felt
towards their injured siblings. Closeness was associated with the amount of time they spent together, the types of activities they engaged in, and the common interests they shared.

Three siblings described changes in their relationships with their parents as well. Lastly, seven of the eight siblings also identified changes in their relationships with their friends. As with the sibling relationships, participants characterized friendships by the amount of time they spent together and the types of activities they shared. Each of these changes will be discussed in turn.

Five of the eight participants experienced changes in the roles they assumed within their families. Two older female siblings reported feeling like mothers to their younger injured brothers. Three male siblings who were all younger than their injured brothers described themselves as playing the role of big brother. In contrast, two older siblings (one male and one female) reported they continued to feel like the big brother and big sister they had always been. Similarly, one male sibling reported playing the role of younger brother as he always had. Participants described the role of mother, big brother or big sister as someone who watches out for, disciplines, encourages and helps a child or sibling.

Whereas those activities were the ones described within Doing what it takes, siblings attributed their role changes to the activities they assumed which were necessitated by the Change in Sibling. Examples siblings gave to describe their change in roles included:

We always had a good relationship and his being six years younger than I, it was always very much older sister, little brother. Now though, he
gets mad and I’ll be like, “now David”. It’s almost like he has two mothers. So I try really hard not to do that, because he has a mother. I try to be someone he can have fun with. (S#1)

Our roles have changed. He’s ended up being the little brother . . . my parents go out of town and leave me with him, so all of a sudden I’ve got a total responsibility change and I’m not the little brother any more. (S#4)

All eight participants described a change in the closeness they felt towards their siblings after they were injured, with four siblings feeling closer and four feeling less close. Closeness was associated with the amount of time they spent together, the types of activities they engaged in, and the common interests they shared. Generally, siblings who reported feeling closer spent more time together and siblings who reported feeling less close spent less time together although there were two exceptions. More time was spent together when siblings felt sorry for their injured siblings or when they could engage in mutually enjoyed activities. Mutually enjoyed activities were things the siblings used to do together, with or without modifications, or new activities in which the injured sibling could participate given his/her impairments. Less time was spent together when the injured sibling exhibited aggressive or hostile behaviour or when the siblings could not find mutually enjoyed activities. Having to modify activities to suit their injured siblings was another change which contributed to a Different Life Rhythm.
Changes in relationships with friends were also described by all participants except one. Generally, siblings who spent more time with their injured sibling spent less time with friends and siblings who spent less time with their injured sibling spent more time with friends. The two exceptions to that were a male participant who reported no change in friendships and a female participant who had a child of her own since the time of the injury and reported spending less time with her brother and her friends. The three siblings who reported spending more time with friends were all male participants. The three siblings who spent less time with their friends also reported trying to include their injured siblings when they were out with their friends. They did so for two reasons; either they included the injured sibling so he/she wouldn't be lonely, or they tried to fulfill their responsibility to watch out for the sibling while continuing with their previous level of social activity.

Participants described the changes in the activities and relationships they shared with their siblings and friends in these ways:

We do lots of things together now. Much more than we ever did socially. Even if its only going to a movie or something. He doesn't have too many friends, so . . . I know that going out with his sister doesn't make up for having a friend, but when I'm going out with my friends I try to include him and he likes that. It's OK. (S#1)
We're not really close. I guess we'll play pool in the basement or something or we'll watch TV or go out and shoot basketball in the driveway. Stuff like that—sporting types of things like that but, I'm really into tennis and hockey and he can't really participate; can't be my partner anymore. I regret that. We don't really communicate on an emotional level, it's more of a... It's almost like I don't feel I can... it wouldn't really occur to me to talk about stuff. I don't know if he could handle it. We've never really had a deep, stimulating conversation. If I have stuff on my mind I guess I automatically talk to a friend. (S#3)

I'll say hello to him; see him in the kitchen. Usually we have dinner together, but that's about it. We play pool sometimes... I hung out with him a lot before his accident. I went to camp with him. We were close. It's just a disappointment. I'm a lot closer with his friends now. I know I should spend more time with him. It's just hard to hang out with someone who doesn't do the same things you do. (S#4)

We're like best friends. If we have problems with our family, we talk to each other. If he has problems at school, I help him out or if I have problems at school or with a teacher he helps me. We never really talked about our problems. Actually we never did. Now, we know we have
problems, like school, work and we help each other as much as we can.
We’re there for each other. (S#7)

Me and Tom are really close. It could be partially that I’m the oldest; that I feel I should take care of him, but I’m sure my sisters feel that way too. It think it is more that we have the same interests. That’s how we became close. I invite him to come because I know that he enjoys it so much that I kind of . . . whenever I went bowling he would come. There’s no problem with him coming, but I cannot take it when my sisters and my brother come with me places cause then I take my attention away from my friends and I worry about them. I don’t know if my friends notice it very much . . . well yes my friends do, but they never say anything to me. (S#8)

Three participants spoke of how they lost friends after their brothers and sisters were injured. There were various reasons for the losses, as these examples illustrate:

I was in an environment where all the kids were going into grade 9, doing grade 9 things. All the girls running around, whatever, and I wanted absolutely nothing to do with that. Like conversations that were going on I could not sit in on because they had absolutely no relevance. Like what are
you talking about? That's not bad. What are you complaining about? Not in pity for myself way, but like just how can you talk about this stuff?

Nothing, no conversations interested me. So it took a little while before I got to hang out with a good group of people that I could talk about relevant things with. (S#4)

Got to stick up for her a lot. People see her, start making fun of her, I have to stick up for her like she used to stick up for us. It's a little bit different now. . . . I guess I may have lost a couple of friends because of that. They'd be making comments about her; I stuck up for her. People didn't seem to understand her as much as we did. No big loss. (S#5)

Before that I was very social. Then for about a year I lost contact with some of my friends because I became totally involved in getting Paul better. I hurt some of my friends by not keeping in contact with them—actually I lost my best friend for sure. We have contact now but it's not like it used to be.

(S#6)

Three siblings also described changes in their relationships with their parents. They described how they felt closer, had better communications, and were given more respect.

They described their experiences in these words:
We shared a lot of responsibility and still do. I definitely feel that finally my parents treat me like an adult. (S#1)

It started off because of Ryan, and the relationship my parents had with him. He was always going out and they didn’t know his friends. They didn’t want to have the same thing with me. They wanted my friends to come over instead of us always going out. So finally I said fine, but you have to respect my privacy and they do. (S#4)

I’ve always been close to my parents, but I had a tendency to move away from them when problems came up. Communication has gotten better. I think because I’m getting older too, we’re able to talk about a lot more things which is good. (S#6)

As the above examples demonstrated, well siblings had to redefine many of their relationships. These changes contributed to their *Different Life Rhythm* and were one part of what made their lives *Forever Different*. The above examples also illustrated the *Mixed Emotions* siblings felt in response to the changes in their relationships. They spoke of being concerned about their siblings; that they not be lonely or alone. They spoke of a sense of obligation to spend time with their siblings, but sometimes not wanting to be with them or resenting that they had to include them in activities. They described feelings of
disappointment and frustration because of the changes in their relationships and the loss of
some friends.

The final two subthemes of *Different Life Rhythm* were *Learning by trial and error*
and *Wanting someone to talk to*. These two themes referred to how siblings coped with the
changes in their lives.

*Learning by trial and error.* *Learning by trial and error* described how siblings
learned to accommodate for their injured siblings' changed abilities. Six of the participants
gave examples of this type of learning. *Learning by trial and error* meant that siblings had
little prior knowledge of how to respond to their changed siblings. They received little
education and had to make it up as they went along. It often involved intuitive or reflexive
reactions. They had to think their way through situations as they were happening. The
following are descriptions of *Learning by trial and error* as given by the participants:

It's been difficult to take the advice or things that these people have
told me and put them into practice with David because I'm not a parent; he
doesn't listen to me the same way and doesn't really react to me. So I've
really had to completely sort of make up my role with him and outside of
the family. That's been kind of hard—not knowing where I stand. Yea, you
know I just kind of muddle along. My parents have this clear cut role and
mine is really fuzzy. I had to make it up as I went along. (S#1)
A: I'd always seen my brother... like you give him a problem and he'd figure it out right away. And after the accident, you'd give him a problem and it would take him a while. I had to get used to it. When I look back now, I was learning what to do with that kind of stuff.

Q: Do you think someone could have helped you along the way?

A: Not really. I think it was a trial and error sort of thing. I just figured it out for myself. (S#2)

It's just something that has developed in me. I think of things before they happen; I see that's how it is. I think of what the potential problem could be before it happens. I think some things are trial and error too. I think it's just... you don't want to have things happen so you just... or else you're right there beside him so you're anticipating what kind of things could go wrong; you're able to remove him from it. (S#6)

Sometimes he gets mad. He'll say something, I'll go downstairs and he'll say "get out". I just start talking to him, trying to calm him down, or I'll just sit with him watching tv. Or I'll ask him to play cards. I try to distract him because he forgets.

Q: How did you learn to do those things?

A: Through experience mostly. I used to get mad, but after a while we
talked about it and I realized he didn’t really mean it, so you can’t really get
mad at him. (S#7)

As the above quotations suggested, well siblings learned how to respond to their
changed siblings through experience. Most described how it was difficult to learn that way,
but some found learning that way natural. There were mixed feelings about having to learn
by trial and error.

*Wanting someone to talk to.* The other coping strategy identified by four of the
participants was *Wanting someone to talk to.* That is, four of the eight well siblings felt
having someone to talk to was an intervention that would have helped them cope with,
adjust to and accept a *Different Life Rhythm.* The type of person they wanted varied from
friends who understood their experiences to professional help. They wanted it both for
themselves and their family members. The concept of coping was not purposefully
explored in this study, but the following comments which describe *Wanting someone to talk
to* were spontaneously received during interviews:

... and it was really hard for a long time to really talk to other
people about it unless you've sort been through a tragedy its difficult to—
you don't want to go on and on about it; its nicer if you can just look at
someone and have them just know they know and give you a hug you know
... and so ... yeah. (S#1)
I don't think we—we've never been a family that really talks about it. I think it may have done us good a few years ago to go to a counselor or something like that—actually go through the process where we could talk about those things because we've never really talked about it. (S#3)

We all struggle with the same thing. I need to find somebody that I can talk to—someone who understand or has been through a similar experience. (S#6)

I guess in terms of programs that could help us, I wouldn't have been aware of them. We have one now and it's been helpful. They come over and it forces everyone to sit down and talk about it which is helpful. (S#8)

As the above examples illustrated, half of the participants felt they and their families could benefit from talking about their experiences. Siblings did not feel that talking replaced Learning by trial and error, as three of the four siblings identified both means of coping with a Different Life Rhythm.

The focus of the results section will now shift from the description of how siblings' lives were different to a description of how they were different as people.
Change in Self

*Change in Self* referred to the changes well siblings experienced within themselves and their way of thinking about life. Within this theme are descriptions of how the siblings are *Forever Different* as people. *Change in Self* was supported by two subthemes—*Change in priorities* and *New appreciation for life*.

*Change in priorities*. One *Change in Self* that all siblings identified was *Change in priorities*. *Change in priorities* meant that well siblings experienced a shift in what they deemed important after their brothers or sisters had brain injuries. Siblings noted that this changed occurred soon after the injury, but they did not experience any internal conflict from the change until they tried to resume all of their previous commitments such as work and school. It was then that they realized they would make decisions and spend their time differently, because their priorities were *Forever Different*. They attributed this *Change in priorities* to two things. The first was a practical reason in that well siblings had less time because of *Doing what it takes*. Their responsibilities at home, necessitated by the *Change in Sibling*, meant well siblings had less time for other things and they had to decide carefully how to spend that time. The second reason was that they had witnessed a significant life event. It was a kind of “wake-up call” that prompted them to rethink who they were, what they wanted to do, and why they were doing it.

For three of the participants, a *Change in priorities* meant changing their focus from more selfish or materialistic interests to helping people. They described:
I was in the film industry before and that was great, but it doesn’t mean as much to me to just go and make movies. So what if you meet some famous people? Like who cares really? What’s important really comes out. . . . Now I’m working with brain injury or women’s groups. (S#1)

Seeing it all happen . . . learning stuff about myself . . . in some ways I can put what I’ve learned into other uses. . . . I always wanted to be by myself, but now I always want to be around people. I always want to help people and be a positive influence on people’s lives. (S#2)

I was in a Phys-Ed program and hoping to get into education. . . . I haven’t gone back to university. I have been taking Early Childhood Education courses and I might go into special needs. (S#6)

For two of the male siblings, a Change in priorities meant focusing on school and work instead of friends and hobbies. They described:

I’m a real loner. I have lot’s of friends; everybody shows up here, but I don’t go out. I’m just wrapped up in my work here. (S#5)
I used to be interested in painting, but now I’m interested in architecture. I’m only in grade nine, but I’ve already started thinking about my career. I don’t even have time for my friends because I’ve got to do my homework—get good grades. (S#7)

For the other three participants, a Change in priorities meant a shift from seeing themselves as the priority to putting their family and injured sibling first. They described:

As soon as I start thinking about what he’s going to do I think you know . . . Is he going to be by himself? What’s he going to be doing? Then I think well you know maybe he could be living with me for a while or something. Then I start thinking about what he’s going to be doing then I think it might have something to do with what I’m doing too. (S#3)

I don’t want to lose something by not having it. I experienced what is important . . . our whole family did. . . . I wanted absolutely nothing to do with people at school. They had no relevance. (S#4)

I worry more about him than I do about my sisters. . . . He is just so vulnerable because of his brain injury and he can still be taken advantage of.
I wish I didn’t have to worry, but I know I will always have to look out for him. That is sad. (S#8)

As the above examples demonstrated, a Change in priorities entailed different changes for different siblings, but they were all Forever Different people because of it. Siblings gave few indications of how they felt about this change; however, the thoughtfulness that was reflected in their quotes indicated how profoundly they were affected by their siblings’ injuries.

New appreciation for life. An aspect of Change in Self that was similar to Change in priorities, but which represented a greater transformation in one’s way of thinking about the world was New appreciation for life. A New appreciation for life was experienced by four of the siblings interviewed. It meant that siblings realized their own mortality and the uncertainty of a long life. They became more cautious in their lifestyles so as to decrease the risk of inadvertently shortening their lifespans. Similarly, they expected others to work towards preventing injury and became anxious when they noticed hazardous situations. Their new appreciation was something they thought about regularly and was evident in how they went about their daily lives. In the words of the siblings:

I have a lot more fear than I used to. I never used to worry. It’s weird.

I used to be a real mad person on my mountain bike and used to go up and down mountains. Now I’m nervous about even just riding around the
neighbourhood. Of course, now I’ve got a helmet. I never wore a helmet before. . . . So it kind of brings it home. It doesn’t always just happen to someone else. (S#1)

It’s made me think. I have a little bit more respect for my life now. I respect helmets a lot more. I always wore helmets, but I appreciate it a lot more. I appreciate life a little bit more too. (S#5)

I think because I got a cold wake-up that there’s more to life than just . . . I think my outlook on life changed, meaning I realized it wasn’t all just fun and life was not just going to be there just for games and playing—I had to become more serious, but I knew to get somewhere I had to put goals ahead of me instead of just going from day to day. I had goals, but I was very spontaneous. I wasn’t sure where I was going. I think that after the accident—after the dust had settled a bit—I became very focused on what I wanted to do and how I was going to do it. In that sense, not everyone my age, but some people my age are still—even now today—partying and stuff like that. (S#6)

I never really thought about the future before. But I guess seeing my brother and how he’s realized how short life can be has made me think
about it too. . . . You know they say you should wear a seatbelt. We never used to, but now it's like as soon as we get in the car we put it on. And yea, life is short. (S#7)

As the four examples illustrated, a *New appreciation for life* was a more existential change than a *Change in priorities*. Siblings were in awe at the degree to which they had changed as people.

**Summary of the Findings**

The experiences of siblings living with a brother or sister who has a traumatic brain injury were presented in this chapter. There was one overarching theme—*Forever Different*. *Forever Different* captured the profound change that occurred in the lives of well siblings after a brother or sister had a TBI. It described how their lives were different than they had been, different than they had expected them to be, different than those of their friends and continually changing. *Forever Different* was supported by four themes which arose from the data analysis. The first of the themes was *Change in Sibling*. *Change in Sibling* outlined the physical, cognitive and behavioural changes injured siblings experienced and was cited by the well siblings as the impetus for changes in themselves and their lives. *Mixed Emotions* was the second theme and it described the conflicting feelings well siblings had about their experiences. The third theme, *Different Life Rhythm*, captured the daily lives of well siblings living with a brother or sister who had a brain injury. It included descriptions of the responsibilities, relationships and activities that contributed to
Forever Different. The final theme was *Change in Self*. *Change in Self* depicted how the well siblings were existentially *Forever Different* as people, after living with a sibling with a brain injury. The findings presented were supported by actual quotations from the well siblings.
Chapter 4: Discussion

A qualitative, exploratory approach was used in this study to generate a description of siblings' experiences of living with a brother or sister who has a traumatic brain injury. No published study has focused on the experiences of the well siblings by interviewing them individually. Other studies asked parents to describe the experiences of their children (Bergland & Thomas, 1991; Brown & McCormick, 1988; Hall et al., 1994; Lezak, 1978; Mauss-Clum & Ryan, 1981; Rivara et al., 1992; Romano, 1974) or interviewed siblings together with their parents (Johnson, 1995) or peers (Willer et al., 1990). Thus, this study offers siblings' perspectives of what it is like living in a family when one sibling has a TBI. The findings will be discussed in light of Family Systems Theory and the empirical literature, according to the emergent themes of the study (see Figure 1).

The overarching finding of the study was that siblings' lives are **Forever Different**. Forever Different means that the lives of well siblings are profoundly changed after a brother or sister has a traumatic brain injury. Their lives cease to be the way they were; there is no going back. Their lives fail to take the course they thought they would; the future is uncharted. Their lives no longer resemble those of their friends; they are different. Their lives are continually changing—forever.

The well siblings in this study attributed the Forever Different nature of their lives to the changes that occurred in their siblings after they were injured. This Change in Sibling, as it was labelled, represented the impetus for the experiences siblings described. Their interpretation of cause and effect is supported by Family Systems Theory. Within
Family Systems Theory each sibling in a family is defined as a unit of the larger family system and all units within the system are viewed as connected. As such, a change in one unit of the system is expected to result in changes in the other units of the system (Kay & Cavallo, 1994; Leaf, 1993; Maitz & Sachs, 1995). Thus, the changes siblings described within their lives and their attribution of those changes to the change in their siblings was to be expected.

There was also the expectation that well siblings would have difficulty dealing with the changes in their injured siblings because of the nature of the injuries. Traumatic brain injuries often result in changes in interpersonal skills, cognitive abilities and behaviours. Prior literature had suggested parents find cognitive and behavioural impairments to be the most difficult with which to deal (Florian et al., 1989; Kreutzer et al., 1992; Livingston & Brooks, 1988). Similarly, studies of children exposed to mental illness in their families suggested they have difficulty dealing with cognitive and emotional symptoms (McLaughlin, 1992; Stambrook et al., 1994). Therefore, the finding in this study that siblings identified the changes in their siblings' cognitive abilities, interpersonal skills and behaviours as difficult to accept is consistent with previous literature. However, the siblings in this study went on to describe why the changes were difficult and frustrating. They found the Change in Sibling to be frustrating because it was elusive. They often could not observe their siblings' impairments directly and thus had a hard time believing they were real. Also, their siblings' abilities and behaviours continued to change over time in an unpredictable fashion and they had no knowledge of what to expect. This continual
and unpredictable change contributed to the *Forever Different* nature of the well siblings’ lives.

In contrast to the *Change in Sibling* which participants saw as the impetus for the *Forever Different* nature of their lives, participants described *Mixed Emotions* as their reactions to change. *Mixed Emotions* were the conflicting, emotional responses well siblings experienced. They recalled feelings of joy and sadness, anger and guilt, resentment, frustration and worry. Their emotions changed over time, with all participants describing a mixture of feelings throughout the time they lived with their injured siblings. This finding confirms the anecdotal reports of well siblings and supports Lezak’s (1986) stage theory of the evolution of family reactions to a brain-damaged member. In published anecdotes by individual siblings, Kasowski (1994) and Maurer (1991) described their own experiences as the siblings of individuals with brain injuries. They too described feelings of confusion, frustration, anger, sorrow and triumph as did the participants in this study. Similarly, based on her clinical experiences, Lezak theorized that families experience numerous emotional reactions after one member has a brain injury, including happiness, anxiety, guilt, depression, and mourning. In that way, this study serves to echo the reports of others. Furthermore, Lezak theorized that family members can be in overlapping stages or shift back and forth between stages. That is, family members can simultaneously experience guilt and anger or happiness and anxiety because they were in or between two stages of adjustment. Also, family members can shift back and forth between stages thus experiencing the emotions of happiness, anxiety, guilt, depression and mourning.
indefinitely. As the siblings in this study experienced *Mixed Emotions* simultaneously and for up to 14 years after their siblings were injured, the results of this study would seem to support Lezak's theory. There are no published articles to indicate that Lezak's theory has ever been empirically tested.

Family Systems Theory offers further explanation of *Mixed Emotions*. In Family Systems Theory, it is suggested that changes within a family system disrupt its homeostasis which can cause stress and discomfort (Friedman, 1981). It is also suggested that when the change is complete and homeostasis has been restored in the family, the associated feelings should resolve. In this study, well siblings living with a brother or sister who had a brain injury continued to experience *Mixed Emotions* at the time of interview, which ranged from 2 to 14 years after the injury. The *Mixed Emotions* included feelings of stress and discomfort. Based on Family Systems Theory one could infer that this is because the family system has not achieved homeostasis or that the family continues to undergo changes which threaten its homeostasis.

This study, and the finding of *Mixed Emotions* in particular, has something to add to our understanding of siblings' emotional experiences. The participants went beyond simply describing their emotions to include rich descriptions of the context of those emotions. They took us into their lifeworld to explain why they experienced the mixed feelings they did. They described anger over loss followed by guilt about the anger and then resentment about the guilt; and joy over a small improvement followed by disappointment about a setback and worry about the cause. They cited the reasons for their
feelings including the loss of an equal sibling, the continual change of the injured sibling, not knowing what to expect, and not knowing how to respond. The emotional experiences of distress, anxiety and depression have been noted repeatedly in previous studies of family members living with someone with a brain injury (Hall et al., 1994; Kreutzer, Gervasio et al., 1994; Livingston et al., 1985; Oddy et al., 1978; Orsillo et al., 1993). However, those studies did not enlighten us about the context of those experiences beyond simple demographic information such as age, relationship to the injured person, and severity of injury. This study has provided new information about the particular aspects of living with a brother or sister with a TBI that conjure Mixed Emotions.

Just as Mixed Emotions and Change in Sibling helped to explain Forever Different, so did the themes Different Life Rhythm and Change in Self. Different Life Rhythm captured the day-to-day experiences of living with a sibling who has a TBI. Well siblings described how their life rhythm was initially upset after their siblings were injured, and how they resumed a different, but more predictable life after living with their siblings for about two years. Life rhythm may be akin to the concept of homeostasis in Family Systems Theory. That is, life rhythm refers to the predictable ups and downs every family experiences because it interacts with other systems. Family systems are not static, but rather they change over time in response to demands and stressors. If the changes are small, the family can accommodate them without structural change thus maintaining homeostasis. If the changes are larger the family will undergo a structural or morphogenic change. The siblings in this study, through their description of a Different Life Rhythm,
suggested that homeostasis was restored at some level in their family systems. However, the ups and downs they experience may be of a more frequent, more variant or more stressful nature than those experienced by most families. Thus, although they have a life rhythm, their lives are **Forever Different** than they had expected them to be and different than those of their friends. This could be related to the continual changes in the abilities and behaviours of their injured siblings and it could contribute to the *Mixed Emotions* siblings experienced up to 14 years after their brothers and sisters were injured.

There were four subthemes which elaborated *Different Life Rhythm* and hence **Forever Different**. The first, *Doing what it takes*, described how well siblings assumed different responsibilities after their siblings were injured. Their responsibilities included both physical chores and cognitive-emotional behaviours such as watching out for, being there for, coaching and teaching their injured siblings. Well sibling responsibilities were different than they had been before and continued to change over time. This finding is supported by a tenet of Family Systems Theory which states that when change takes place within a family, the members of that family take action to deal with the change in order to return the family to a state of homeostasis (Kay & Cavallo, 1994; Leaf, 1993). Thus, one would have expected that when one sibling in a family experiences change such as after a TBI, the other siblings have to assume new behaviours. Moreover, just as the abilities of the injured sibling continue to change over time and thus disrupt the homeostasis of the family system, so too would the behaviours of the well siblings be expected to change over time in order to restore homeostasis. Therefore, what siblings’ described as *Doing what it
takes represents their role in maintaining some predictability or homeostasis in the

*Different Life Rhythm*.

The finding of *Doing what it takes* contributes new information about our understanding of well sibling responsibilities when living with a brother or sister who has a TBI. Previous studies were criticized for concluding that well siblings assume greater responsibilities at home after a sibling is injured without providing detailed descriptions of the responsibilities (Gallo et al., 1991; McHale & Gamble, 1989; Tritt & Esses, 1988; Willer et al., 1990; Williams et al., 1993). Filling this gap in understanding was one purpose of this study. Much to this researcher’s surprise, participants had difficulty listing their responsibilities. There were some easily identified tasks such as laundry and housework, but many of their responsibilities were less tangible and required explanation based on a description of the injured sibling’s behaviour. For example, when the injured sibling was agitated, the well sibling might try to distract him/her. If the injured sibling was crossing the street inattentively, the well sibling might have to remind him/her to watch for cars. The study design allowed participants the opportunity to describe their responsibilities in detail and the complexity of *Doing what it takes* explains why the closed-ended questionnaires and interviews used in previous studies were unable to glean a detailed description of sibling responsibilities.

*Doing what it takes* was described by both male and female siblings. This does not support the results of two previous studies which suggested that girls, especially when they are older, may be given greater responsibilities than boys in families with children who
have brain injuries (McHale & Gamble, 1989; Williams et al., 1993). However, two out of the three female participants in this study reported that they were going to be the legal guardians for their injured siblings when their parents were no longer able. None of the male participants mentioned such a responsibility. This finding suggests there might be a gender difference in the responsibilities assumed by the siblings in this study. This finding must be interpreted with caution as the issue of guardianship was not asked directly, but rather spontaneously mentioned by the two participants noted above.

The second subtheme of *Different Life Rhythm* was *Redefining relationships*. *Redefining relationships* described how the relationships of well siblings with others changed after their brothers and sisters were injured. All siblings reported a change in how close they felt towards their injured siblings, where they defined closeness as the time spent together. Some siblings reported feeling closer and some reported feeling less close, but all saw their relationships as different than they had been and different than they had expected them to be, thus supporting the overarching theme of *Forever Different*. The change in closeness seemed to represent a conscious choice, with some siblings choosing to spend more time with their injured siblings and others choosing to spend the minimal amount of time requested by the family. Those who spent more time accommodated the sibling in social outings and found activities they could enjoy together regardless of limitations. This choice was not associated with the strength of the prior relationship, gender, age, length of time since injury or level of functioning of the injured sibling. This finding is consistent with the seemingly conflicting results found in the literature review wherein some studies
suggested there is increased conflict between siblings after one has a brain injury (Bergland & Thomas, 1991; Lezak, 1978; Rivara et al., 1992) and other studies suggested there is increased concern (Johnson, 1995; O’Hara et al., 1991; Willer et al., 1990). It may be that siblings respond with either increased concern or by distancing themselves. This may represent two different ways of coping with the experience.

Besides a change in closeness, *Redefining relationships* also included a change in roles. Seven of the eight siblings reported feeling either like mothers or big brothers/sisters towards their injured siblings, even those well siblings who were the younger sibling. This is consistent with the finding of Willer et al. (1990) in which a group of seven well siblings, all except one of whom were younger than their injured brothers, reported feeling like assistant parents. In that study and this one, siblings attributed the change in roles to *Doing what it takes*. Well siblings had to watch out for, be there for, protect, encourage and in some cases discipline their injured siblings. Performing those activities changed the well siblings’ day-to-day lives and in that way contributed to the *Different Life Rhythm*. Performing those activities was also what made the siblings feel like the big brother, big sister, or parent. Family Systems Theory helps to explain this finding. Within any family system there is a hierarchy with each member having a different amount of power and authority (Maitz & Sachs, 1995). In most families, the parents have the most power and authority, with the siblings following thereafter in birth order with gradually decreasing amounts of power (Maitz & Sachs, 1995). When the well sibling is given the responsibilities of watching out for and disciplining the injured sibling, the well sibling has
power over the injured sibling. This raises the place of the well sibling in the family hierarchy to where he/she feels at the level of a big brother, big sister or parent.

The third subtheme of *Different Life Rhythm* was *Learning by trial and error*. *Learning by trial and error* described how the well siblings acquired the skills and knowledge to assume their new responsibilities and perform their new roles that were part of a *Different Life Rhythm*. *Learning by trial and error* meant that well siblings were often experimenting in their behaviours, acting instinctively, and modifying their actions according to how the sibling responded. Just as the injured sibling changed over time and the responsibilities of the well sibling changed, *Learning by trial and error* continued forever. The learning was *Forever Different*. Of the six siblings who identified with this style of learning, two found it to be a logical and natural way to learn, while the other four found it to be a frustrating and exhausting experience. The vivid accounts given by the siblings were moving and led the researcher to question if *Learning by trial and error* with the accompanying feelings of frustration and exhaustion was a necessary or inevitable process. Conversely, if some siblings find it a natural method of learning, can they be assisted in some way. Family Systems Theory provides no further explanation as it does not address how family members are to learn the new behaviours necessary to deal with a change within the family. Similarly, there were no published studies which explored how siblings learned to assume the roles and responsibilities within a *Different Life Rhythm*. Thus, *Learning by trial and error* represents new information about the experiences of well siblings who live with a brother or sister with a TBI.
The fourth and final subtheme of *Different Life Rhythm* was *Wanting someone to talk to*. *Wanting someone to talk to* was identified by only four participants. It captured how some well siblings wanted to talk about their experiences, despite the fact that some of them had already received professional counselling or described their families as good communicators. The siblings who did not identify *Wanting someone to talk to* included siblings who had and had not received professional counselling as well. Wanting to talk about their experiences and feelings is consistent with previous studies in which siblings (O'Hara et al., 1991) and family members (Brown & McCormick, 1988; Campbell, 1988; Kreutzer, Serio & Bergquist, 1994) identified the same need. The well siblings in this study each had their own idea of what might be helpful with one suggesting individual counselling, another suggesting family counselling, another suggesting an informal (perhaps peer) support and one not having a specific suggestion. This is consistent with the limited available research in which siblings have identified family counselling (Willer et al., 1990), individual counselling (O'Hara et al., 1991) and peer support (Kreutzer, Serio et al., 1994; O'Hara et al., 1991) as three means to be able to talk about their experiences and feelings.

The final theme within the overarching theme of *Forever Different* is *Change in Self*. *Change in Self* captured the change siblings experienced within themselves; how they were *Forever Different* as people. It included descriptions of how their values and priorities changed after living with a sibling who has a TBI. This finding is consistent with Family Systems Theory. In the theory it purports that individual units within the system
may experience changes in behaviours, roles, values and expectations as the system changes (Leaf, 1993; Maitz & Sachs, 1995). What was not expected or explained by the theory was the existential nature of the change.

The *Change in Self* included a *Change in priorities* and a *New appreciation for life*. *Change in priorities* meant a shift in focus from self to family, increased emphasis on school and work, and a new desire to help others. Each well sibling experienced his or her own combination of those priorities. Although all siblings reported a *Change in priorities* and a change in responsibilities (*Doing what it takes*), they did not all express a shift in priorities such that their families were their first priority. Therefore, the *Change in priorities* is unlikely the simple consequence of increased familial responsibility. *New appreciation for life* was expressed by only half of the participants. They described how they became aware of their own mortality and more appreciative of life. They changed their behaviours so as to preserve their lives and promote a meaningful existence. Previous anecdotal literature suggested siblings may experience the type of transformation captured in *Change in Self*. Maurer (1991) recalled being filled with a sense of triumph when his brother spoke. He felt he had witnessed a resurrection and in some odd way had received a gift. Similarly, one sibling in the anecdotal report by O’Hara et al. (1991) described how she was more appreciative of people and had learned the value of life. This study is the first to provide empirical support for those anecdotal reports. What this study does not provide is an explanation of why the siblings experienced a *Change in Self*. It may be the sudden nature of the injury; the fact that the traumas were often preventable accidents. It
may be that the injuries occurred to previously healthy, young individuals to whom the siblings were close. Based on the data, this study offers only speculation as to the reasons behind the *Change in Self*.

In summary, the findings of this study have provided support and clarity for some prior findings and contributed new insights about the experiences of siblings living with a brother or sister who has a traumatic brain injury. The overarching theme of *Forever Different* provides a new way to conceptualize the experiences of well siblings. The theme *Change in Sibling* was consistent with the results of previous studies, but siblings’ descriptions of why the change was difficult provides new insights into their experiences. Similarly, the emotions described within the theme of *Mixed Emotions* were consistent with prior literature, but siblings’ accounts of why they felt *Mixed Emotions* offers new information about the sibling experience. The theme *Different Life Rhythm* allows new insights into the responsibilities and role changes of well siblings, while clarifying the results of prior studies which found increased concern and increased conflict between siblings after one had a brain injury. It also suggests one way siblings learn to assume their new responsibilities. Finally, the theme *Change in Self* provides the first empirical support for the prior anecdotal reports which suggested the experience of living with a sibling with a TBI could have a profound and existential impact on the well siblings.
Chapter 5: Summary, Implications and Conclusion

Summary of the Study and the Findings

This study was inspired by the researcher’s concern for the well siblings living with brothers or sisters who have traumatic brain injuries. This researcher had noticed that well siblings are often profoundly affected, yet excluded from the rehabilitation process, when their siblings have traumatic brain injuries. The work of others highlighted that there was little known about what siblings experience, and what was known was based primarily on their parents’ reports. This study was undertaken to explore siblings’ experiences of living with a brother or sister who has a traumatic brain injury for the purpose of understanding how a change in one sibling in a family affects another sibling in the family.

A phenomenological approach combined with McCracken’s Long Interview Method was used to conduct the study. These methods were implemented because of their fit with the exploratory nature of the study. Family Systems Theory, along with current empirical work, guided the study design and analysis. The study was conducted in a large metropolitan area in southern Ontario. Eight well siblings were interviewed during the study, three of whom were females and five of whom were males. Long interviews of one to two hours yielded rich data about the well siblings’ experiences of living with a brother or sister who has a traumatic brain injury. The data were analyzed to derive the following major findings.

The overarching theme of the study was that the lives of well siblings were Forever Different after the brain injuries of their brothers and sisters. Their lives were different
than they had been, different than they had expected them to be, different than those of their friends, and continually changing. *Forever Different* was supported by four themes.

There were two themes which pervaded the findings and supported the overarching theme. The first, *Change in Sibling*, captured the well siblings’ perception that the differences they experienced in their lives and themselves was a direct result of the changes in their injured siblings. The second, *Mixed Emotions*, described well siblings’ feelings about their experiences.

The third theme, *Different Life Rhythm*, captured the changes in the siblings’ day-to-day responsibilities, activities and relationships. Siblings experienced changes in their responsibilities, with some siblings taking on more, some less and some just different responsibilities. However, all of their stories had a sense of obligation to the family and all but one sibling described a responsibility of having to do whatever it takes. Siblings learned to fulfill their responsibilities through a process of trial and error. Half of the siblings identified that having someone to talk to would have helped them through their experiences.

The final theme, *Change in Self*, acknowledged that the siblings experienced personal changes in what they valued and who they were as people. For half of the siblings, this change included an existential change in their view of life and a shift towards a more focused and cautious lifestyle.
Limitations of the Study

The sampling procedure used in this study limits the fittingness of the results. A convenience sample was obtained which raises the possibility that the sample was a select group. Participants were recruited through either a Head Injury Association or a rehabilitation centre which suggests they had access to support and services at the time of the study. This would not be the case for all families living with a family member who has a brain injury, especially those outside a metropolitan area like the one in which this study was conducted. Also, all of the injured siblings were engaged in some form of community-based work or school which suggests they may be higher functioning than many individuals with brain injuries. Therefore, this study provides only initial insights about the experiences of some siblings living with a brother or sister who has a TBI.

Implications of the Study for Research, Theory and Practice

This study explored and described the experiences of siblings who were living with a brother or sister who has a traumatic brain injury. Their experiences were discussed in light of past research and Family Systems Theory. Based on those findings, the following recommendations are made for research, theory and practice.

Implications for Research

This study has given us some insights into what well siblings experience when living with a brother or sister who has a traumatic brain injury. However, given that the sample was one of convenience, repetition of the study with a larger sample is recommended. Furthermore, studying persons over time in a longitudinal design would
allow the collection of information about sibling experiences as they occur. This would eliminate recall bias and likely provide even more vivid accounts. A longitudinal design would also enable us to study sibling experiences at various development stages. Interviewing the injured sibling, as well as the well sibling, would provide a different perspective of the sibling relationship. Finally, adding some objective measures of the emotions siblings frequently described such as worry, frustration and anxiety would allow us to quantitatively assess the nature and extent of these emotions over time.

The study could also be replicated with slightly different populations. For example, this study focused on siblings with traumatic brain injuries. A similar study could be done wherein siblings with other types of acquired brain injuries are studied. This would provide us with information about whether the nature of the injury has an impact on the experiences of the well siblings.

Finally, the study could be replicated with different sibling combinations. For example, one could study female siblings with male siblings who are injured; or siblings who are younger than their siblings who are injured. These types of studies would examine the effects of age and gender on the sibling experience.

Implications for Theory

In this study, Family Systems Theory was used to interpret the findings. The overarching finding of Forever Different captured the ongoing change that families experience when one member has a TBI. Families may achieve a level of homeostasis, but their lives are not static and the concept of homeostasis cannot be interpreted in that way.
The concepts of Family Systems Theory are challenged by families in which there is continual change such that *Mixed Emotions* of stress and discomfort persist. Also, the subtheme of *Learning by trial and error* illuminated that Family Systems Theory does not suggest how individuals in a system are to learn or acquire the skills and knowledge they need to help the system deal with continual change.

**Implications for Practice**

This study generated initial insights about the experiences of siblings who are living with a brother or sister with a TBI. Although the experiences described herein should not be assumed to represent those of all siblings, clinicians can profit from the findings. Health care providers and social support workers need to be aware of the types of experiences well siblings may have when living with a brother or sister who has a TBI. Clinicians need to view siblings as potential consumers of service throughout the rehabilitation process. They need to be cognizant of the thoughtful, reflective nature of even young siblings who might want to share their experiences. As well, siblings may sometimes want to be resources in the rehabilitation of their brothers and sister. Siblings occupy a unique position within families that likely enables them to contribute to the discussions of and interventions for the rehabilitation of their injured siblings.

There are areas which clinicians should be assessing. First, clinicians should explore the impact the experience of having a brother or sister with a TBI has had on the siblings. The findings from this study suggest it can be a life-altering event for at least some siblings. Another area to examine is emotional experiences. Clinicians need to be
aware that siblings can experience numerous and conflicting emotions from the time of the injury for an undetermined amount of time. Also, clinicians should assess any changes in the roles or responsibilities siblings assume within the family. These may indicate areas where further education or support are required. As well, clinicians may need to look at changes in the siblings as people and to assess their impact on siblings’ well-being and their ability to cope with those changes. For example, siblings may experiences changes in priorities and lifeview which are different than those experienced by their friends. Lastly, the experiences and needs of well siblings can change over time, and thus assessments and opportunities for intervention need to be available across a continuum for many years after the acute injury.

**Conclusion**

The experience of living with a brother or sister who has a traumatic brain injury is a profoundly life-altering event for well siblings such that their lives are *Forever Different*. *Forever Different* means that their lives are different than they had been, different than they had expected them to be, different than those of their friends and continually changing. In their lives, they take on new responsibilities, new roles, new priorities and new meaning all of which entail a great deal of learning and emotion—learning and emotion which could be supported through the work of perceptive clinicians. It is hoped that because of the insights shared by the eight individuals in this study, health care and social support providers working with families wherein one member has a brain injury will think to ask well siblings about their experiences and include them in the rehabilitation process.
References


Appendix A

Introductory Letter

As you will recall, I spoke with you regarding the study I am conducting as part of the Master of Science program in the Department of Nursing Science at the University of Toronto. I am writing to confirm that your organization is still interested in helping me to identify potential subjects for my study.

The purpose of the study is to learn about the experiences of well siblings who live with a brother or sister who has a traumatic brain injury. I hope that knowledge about their experiences will help health care professionals to better understand and care for well siblings. The study is being conducted under the supervision of Dr. Donna Wells who is an assistant professor in the Department of Nursing Science. Ethical approval for the study has been obtained from the Office of Research Services, University of Toronto (see attached).

The study will involve a private interview of approximately one to one and a half hours with each sibling who participates. I will accept only one sibling per family to ensure that I receive data from the siblings of several families. I would like to interview 8 to 12 siblings in total and have approached several different organizations for assistance. I am requesting your assistance in informing potential participants about the study.

I would appreciate it if you would distribute the enclosed letter to potential participants. In the letter I ask family members who are interested in hearing more about
the study to inform you or to call me. If interested family members approach you, please give them a copy of the letter and ask them if you may give me their name and phone number. I will call you on a regular basis to get the names and numbers of those who are interested. I will call them to explain the study further and to arrange an interview.

All interviews will be conducted in a place and at a time of convenience for the siblings. Some siblings may feel more comfortable having their interviews at the Head Injury Association office. With your permission, I would like to have this option available.

Siblings may not directly benefit from being in the study, although they may benefit from sharing their experiences. Also, their participation may help other siblings like them in the future. I will make the results of the study available to them and to your association.

I am available to answer any questions about the study and can be reached at 519-886-9007. Dr. Donna Wells can be reached at 416-978-2854.

Sincerely,

Donna Gill, RN, BScN, MSc (Student)
Appendix B

Letter of Introduction about the Study

Donna Gill is a registered nurse who works in brain injury rehabilitation. She is also a Master of Science student in the Department of Nursing Science at the University of Toronto. As part of her program, she is doing a study with Dr. Donna Wells of the University of Toronto. The purpose of Ms. Gill's study is to learn about the experiences of brothers and sisters who live with a young person who has a traumatic brain injury.

Ms. Gill is looking for brothers and sisters who may be interested in being in the study. Being in the study will involve an interview between the brother or sister and Ms. Gill for about one to one and a half hours. She will ask them to describe their experiences as the brothers and sisters of a young person who has a brain injury. The brothers and sisters who choose to participate can withdraw from the study at any time.

If you or someone in your family might be interested in hearing more about the study please give me your name and phone number and I will pass it on to Ms. Gill. You can also contact Ms. Gill yourself and the number is 519-886-9007. You are welcome to take a copy of this letter which also lists the criteria individuals must meet to be included in the study.

Sincerely,

Donna Gill, RN, BScN, MSc (Student)
Appendix C

Letter of Explanation about the Study

My name is Donna Gill and I am a registered nurse who works in brain injury rehabilitation. I am also a Master of Science student in the Department of Nursing Science at the University of Toronto. As part of my program, I am doing a study with Dr. Donna Wells of the University of Toronto. The purpose of my study is to learn about the experiences of brothers and sisters who live with a young person who has a brain injury.

If you agree to be in the study, I will interview you for about one to one and a half hours. We will meet at a place and time that is convenient for you. I will ask you to describe what life is like for you as a brother or sister living with someone who has a brain injury. I will also ask you some specific questions about your life. There are no right or wrong answers. You do not have to answer any question you don't want to. You may become upset during the interview. You can stop the interview at any time. You will be assisted to seek appropriate support if necessary. If your family is upset by the study, they will be assisted to seek appropriate support as well.

Your name and the names of your family members will not be printed in any reports of the study. No one will know what you told me. You may be able to recognize your words or ideas in the reports, but no one else will. The only time I may have to tell someone what you said is if I feel the safety of yourself or others is threatened. If this happens, I will talk to you first and then contact the appropriate person.
Being in the study may not help you directly, but you may benefit from talking about your experiences. The results of the study may help other people like you in the future.

It is important that what you tell me during the interview is recorded word for word. To ensure this, I will audio-tape-record the interview. The audio-tape recordings will be kept in a safe place by me and will be destroyed when the study is complete.

I may need to call you after the interview to clarify things you told me.

If you have any questions about the study please call me at 519-886-9007 or Dr. Donna Wells at 416-978-2854.

Sincerely,

Donna Gill, RN, BScN, MSc (Student)
Appendix D
Consent Form for all Siblings

I, ____________________________ agree to take part in Donna Gill's (name of sibling) study of siblings' experiences of living with a brother or sister who has a traumatic brain injury.

I have read and understood the letter of explanation about the study. I understand that the purpose of the study is to learn about the experiences of brothers and sisters who live with a young person who has a traumatic brain injury.

I understand that I will be interviewed for about one to one and a half hours. I do not have to answer any question I don't want to. I may be upset during the interview. I can stop the interview at any time. Donna Gill will help me and my family get support if it is needed.

I understand that I may not benefit directly from being in the study. Other people like me may benefit in the future.

I understand that what I say will be audio-tape-recorded. I understand that Donna Gill will keep the audio-recordings in a safe place. I understand the audio-recordings will be destroyed when the study is complete. My name and the names of my family members will not be printed in any reports of the study.
I understand that if I tell Donna Gill anything that makes her think the safety of myself or others is threatened, she will have to report it to the appropriate person. I understand she will talk to me first, before telling anyone else.

(Date)  (signature of sibling)

I have explained the nature of the study to the sibling and I believe that he/she has understood it.

(Date)  (signature of researcher)
Appendix E

Consent Form for Parents of Siblings Under 16 Years of Age

I, __________________________ agree to allow my son/daughter __________________________
(name of parent) (name of sibling)
to take part in Donna Gill's study of siblings' experiences of living with a brother or sister who has a traumatic brain injury.

I have read and understood the letter of explanation about the study. I understand that the purpose of the study is to learn about the experiences of brothers and sisters who live with a young person who has a traumatic brain injury.

I understand that my son/daughter will be interviewed for about one to one and a half hours. My son/daughter may refuse to answer questions or withdraw from the study at any time. My son/daughter may become upset during the interview. If this occurs, the interview will be stopped and my son/daughter will direct if and when the interview will continue. My son/daughter will be assisted to seek appropriate support if necessary. If our family is upset by the study, we will be assisted to seek appropriate support as well.

I and my son/daughter may not benefit directly from being in the study. Other families like us may benefit in the future.

I understand that the information my son/daughter provides will be audio-tape-recorded. I understand that Donna Gill will keep the audio-recordings in a safe place. I understand the audio-recordings will be destroyed when the study is complete. My
son's/daughter's name and the names of our family members will not be printed in any reports of the study.

I understand that if my son/daughter tells Donna Gill anything that makes her think the safety of my son/daughter or others is threatened, she will have to report it to the appropriate person. I understand she will talk to my son/daughter first, before telling anyone else.

I believe that my son/daughter understands the nature of the study. I believe that my son/daughter wants to participate.

__________________________  ________________________
(Date)                       (signature of parent of sibling)
1. Introduction

- I would like to thank you for volunteering to participate in the study. At this time I would ask you to review the letter of explanation about the study. (allow time for reading)
- Do you have any questions about the study? (allow time for questions)
- I would like you to read and sign the consent form at this time. (Have the subject sign two copies and give one to him/her).
- Repeat the above steps with a parent if the sibling is under 16 years of age.

2. Demographic Profile

Now I am going to ask you some general questions that will help me get to know you.

Remember, you don't have to answer any question you don't want to. Just take your time. There is no rush. There are no right or wrong answers. Let me know if you want to take a break or stop.

Today's Date: ________________ Interview Location: ____________________________

Name of subject ____________________ Age of subject ____ Sex of subject _____

Name of sibling with TBI ________________ Age of sibling with TBI ____
Sex of sibling with TBI ___  Length of time since the TBI ______________________

Length of time living with the sibling since the TBI ______________________

Thank you very much.

3. Interview Questions

Now I am going to ask you about your experiences.

**Grand-tour question:**

1. Tell me what it is like living with a brother/sister who has a brain injury?

   **Use floating prompts to sustain dialogue such as nodding, saying yes/un-huh, repeating single words with inflection.**

   **Make notes of words, phrases, or ideas that should be returned to later in the interview.**

**Contrast questions:**

1. Is your life different than it was before your brother's/sister's injury?

   a) How is it different?

   b) What is it like now?

   c) How do you feel about that?

   d) Why do you think it is different?

   e) Do you think it is because of your brother's/sister's injury?
2. Is your relationship with your brother/sister different than it was before his/her injury?
   a) How is it different?
   b) What is it like now?
   c) How do you feel about your relationship now?
   d) Why do you think it is different?
   e) Do you think it is because of your brother's/sister's injury?

Category questions:

1. Do you think your family has changed because of your brother's/sister's injury?
   a) How has it changed?
   b) What is it like now?
   c) How do you feel about that?

2. Do you have specific responsibilities at home?
   a) What are they?
   b) Are they different than they were before your brother's/sister's injury?
   c) What is it like for you to have those responsibilities?

3. Do you think the rest of your life has changed because of having a brother/sister with a brain injury?
   a) How has it changed?
   b) How do you feel about those changes?
   c) What about school? Have things changed at school?
d) What about your friends? Have things changed between you and your friends?

e) What about other things like sports and clubs?

4. How does having a brother/sister with a brain injury make you feel?

a) Other people have reported feeling worried, angry, frustrated, sad, and more independent. How do you feel?

4. Summary

- Is there anything else you would like to tell me? Anything you think might be important for me to know about your experiences.

- Do you have any questions you want to ask before I go?

- May I call you if I need to clarify anything you have told me?

Thank you very much for being in the study.

5. Post-interview Summary

**The researcher will ask herself the following questions immediately after the interview.

1. What were the main issues or points that struck me in this interview?

2. Summarize the information received from each interview question.

3. What changes should I consider for the next interview?
## Appendix G

### Master List of Subjects

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Appendix H

List of Codes and Descriptions

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Appendix I

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