

**PARENTAL COPING FOLLOWING ONSET
OF
CHILDHOOD BRAIN INJURY**

by

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**A thesis submitted to the School of Rehabilitation Therapy
in conformity with the requirements for
the degree of Master of Science**

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Abstract

The purpose of the following study was to enhance the understanding of the family environment subsequent to the acquired brain injury (ABI) of a child, through the investigation of individual parental coping strategies, the relationship that exists between maternal and paternal coping strategies, and the extent to which social support and family environment affect parental coping.

A cross-sectional design was used in which 30 parents, corresponding to 15 children with acquired brain injury completed the Ways of Coping Scale (Lazarus & Folkman, 1988; revised McColl & Skinner, 1995b), the Types of Support Questionnaire (revised from the Interpersonal Support Evaluation List Cohen et al., 1985 by McColl & Skinner, 1995b), the Family Environment Scale (Moos, 1974) and provided relevant demographic data pertaining to the study.

The outcomes of the study resulted in 4 main findings. First, the prominent types of coping strategies used by the parents were perception-focused strategies. Coping strategies directed at altering the perception of the acquired brain injury were most commonly reported. Second, the mothers utilized a larger coping repertoire than the fathers. Mothers reported using more strategies often or always when compared to fathers. Third, a relationship between maternal and paternal coping was found. The results suggest that the relationship was complementary in nature. That is, when one parent employed a coping strategy a great deal, the other parent did not. Last, relationships between coping and social support and coping and the family

environment were found. A relationship existed between instrumental or practical support and emotion-focused coping, as well as between family cohesion and perception-focused coping.

The parents of a child with ABI are important determinants of their child's health; financially, medically, and emotionally. To a large extent, family health and functioning are a repercussion of decisions and reactions employed by parents. Clinicians need to help parents to recognize and understand parental coping styles, and enhance the development of positive strategies, including perception-focused strategies, as well as underscoring the importance of social support and the family environment in successful adaptation. Paying close attention to parental coping strategies, identifying limits of current coping and implementing appropriate intervention, will positively modify the family environment, enabling adjustment for all family members.

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***For Laura,
whose inspiration guides me.***

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Chapter 1: Introduction

Impact of Pediatric Acquired Brain Injury on Families

Recent estimates indicate that 219.4 children per 100 000 annually sustain an acquired brain injury (ABI) that necessitates ongoing comprehensive medical care in Canada (Provincial Report, 1999; Watt, 1999). Acquired brain injury is damage to the brain that occurs after birth and is not related to a congenital neuro-developmental disorder. The damage may be caused by traumatic injury to the head associated with, for example, motor vehicle accidents, sports related injuries or falls, or it may also be due to non-traumatic causes such as stroke, encephalitis, or an aneurysm (Zink, 1996). An ABI usually has a definite onset, and in most cases, survivors are left with physical and cognitive impairments (Whyte & Rosenthal, 1993). As well, changes in behaviour, mood (emotionality), and personality after ABI have been documented by many investigators, and are considered by clinicians to be among the most difficult disabilities to manage effectively (Kaitaro, Koskinen & Kaipio, 1995; Whyte & Rosenthal, 1993).

The economic cost and social impact of acquired brain injury is considered enormous. For many individuals, ABI results in an abrupt transition from a predictable lifestyle to a state where competencies have changed and expectations for the future are uncertain. Besides the individual, family equilibrium is disrupted as family members experience their own process of adjustment to the ABI and its consequences. The onset of an ABI has been viewed as a source of prolonged stress on the family as physical,

emotional and social effects extend long after the time of initial diagnosis (Feigin, 1998). The adjustment process following an event of ABI, therefore, becomes a shared family experience whose ramifications need to be understood (Feigin, 1998).

The outcome of an ABI usually results in highly significant emotional events and losses for the family, which necessitate coping efforts. Coping is the process through which the individual manages the demands of the person-environment relationship that are appraised as stressful, and the emotions they generate (Lazarus & Folkman, 1984). Coping and adaptation are distinct concepts. Coping is “the process of coming to terms with a challenge and adaptation is the result” (Murphy, 1962, p.6). Over the past two decades, little information about the processes underlying successful coping and adaptation following the onset of acquired brain injury has been obtained (Quittner Espelage, Opiari, Carter, Eid & Eigen, 1998).

Factors Affecting Coping and Adjustment of Families

The existing ABI literature has focused on survivors, yet some researchers believe that families suffer as much, if not more, than the survivors themselves (Testani-Dufour Chappel-Aiken & Gueldner, 1992). Investigators have attempted to predict family member adjustment on the basis of survivor variables, such as injury severity and/or types of impairment. Emotional and behavioural changes in the survivor have been reported to be related to the relative's burden and psychological distress (Douglas & Spellacy, 1996; Sanders, High, Hannay & Sherer, 1997). Another factor important in

predicting burden was the caregiver's rating of their satisfaction with their ability to cope with the work of caregiving (Knight, Devereux & Godfrey, 1998). Studies suggest families are often at increased risk for family dysfunction, and those who cope poorly may be at greatest risk for adverse consequences (Max, Koele, Smith, Sato, Lindgren, Robin & Arndt, 1998; Wade, Taylor, Drotar, Stancin & Yeates, 1996).

From 1975-1995, few systematic, hypothesis-driven investigations of the impact of childhood ABI on family functioning were conducted (Wade, Taylor, Drotar, Stancin, 1995). The general aim of these investigations was to identify the challenges posed by pediatric ABI and its sequelae on family functioning. Certain factors, such as parental psychological disorder, appear to place families at greater risk for long term dysfunction (Wade et al., 1995). Injury severity accounts for a portion of the variance in child outcomes after ABI, but considerable variability in outcomes is observed even among the most severely injured (Fletcher & Levin, 1988). Rutter, Chadwick and Shaffer (1983) noted parental anxiety in response to altered parent-child relationships and marital tensions. In a study conducted by Perrott, Taylor and Montes (1991) parents reported higher levels of stress associated with parenting the child with ABI than in parenting of siblings. Rivara and colleagues (1992) noted that preinjury family functioning and coping, along with rating's of the child's premorbid behaviour, predicted which families would be most adversely affected, above and beyond injury severity. Harris and partners (1989) reported that 40% of the families in their sample experienced changes in family composition, including parental separation and divorce, following pediatric ABI. Another study examined how traumatic brain injury (TBI) in adolescents affected

parental marital functioning, and the relationship between multiple aspects of marital functioning (Thompson, 1997). The parents of adolescents with TBI were found to experience more global marital distress, than parents of children without TBI. Fathers tended to describe their marriage more positively than mothers. Mothers reported greater global marital distress, less satisfaction with the frequency and amount of marital communication, and dissatisfaction with the management of family finances. Thompson's (1997) finding supports literature which suggests that intact and communicative families may be able to cope more effectively with the trauma of the injury than families in which there is less cohesiveness, thereby underscoring the importance of identifying predictors of resilience and adaptation (Rivara, 1994).

Parental Coping with Childhood Illness and/or Disability (Related Literature)

Most of the review studies of the general literature regarding gender differences in coping have reported on studies that utilized standardized questionnaires. According to a review by Nieuwenhuizen and Ridder (1994), the literature is inconclusive concerning gender differences. Verbrugge's review (1985) concludes that men are found to prefer more active, problem solving and tension reducing coping behaviour and that women prefer to use social support and emotion focused coping styles. These gender differences were also found in a recent study by Ptacek and colleagues (1994). However, another study (Porter & Stone 1995), about coping with daily stressors showed no gender differences. Although findings of the general literature are relevant, the context specific nature of the present study required a review of other childhood traumas, namely

pediatric cancer and pediatric disability. The similarity in these experiences to that of pediatric ABI, including definite onset, acute hospitalization, and changes in family routine allow for comparisons between these populations to be made.

Pediatric Cancer Literature

The diagnosis of cancer in a child has a devastating impact on both the child and parents. The life threatening nature of the illness (40% of children do not survive their illness) which involves invasive treatment, distressing side effects, uncertainty about survival, repeated hospitalizations that disrupt normal family routines, and changes in usual roles and responsibilities have implications not only for each family member, but also for the whole family system (Kazak, 1994). It is suggested that even though acquired brain injury and cancer are unique diagnoses, their outcomes and effects on the family system share commonality, relevant to this study.

Coping, Marital Satisfaction and/or Psychological Distress

A review of the literature indicates that the majority of studies have examined coping in parents of pediatric cancer patients in relation to marital satisfaction and/or psychological distress. Two studies that solely investigated the differences between mothers and fathers in their use of coping strategies have been documented. Chesler and Barbarin (1987) observed that fathers used more denial coping strategies than mothers, and that mothers utilized more religion and information seeking coping strategies than

fathers. Larson and colleagues (1994) found that mothers used more active-coping strategies than did fathers.

In terms of parental coping following pediatric cancer and psychological distress, gender differences were examined in a recent study (Hoekstra-Weebers, Jaspers, Kamps, Klip, 1998b). Fathers used more active problem-focused strategies at diagnosis, and less at 12 months post-diagnosis than did the mothers. Mothers were reported to have used more social support seeking as a coping strategy, than did fathers. A tendency for similarity in the use of coping styles within couples was found, with respect to the relationship between maternal and paternal coping strategies.

The preponderance of studies have investigated parental coping and marital satisfaction in parents of childhood cancer survivors. Kupst and Schulman (1988) reported that overall family coping was positively related to the quality of the marital relationship. That is, the psychosocial adaptation of the family to the child's leukemia was directly proportional to the satisfaction of the marital relationship. In another study of parents of pediatric cancer patients by Koocher and O'Malley (1981), marital difficulties arose when partners used different coping styles. A positive association between marital quality and complementarity (one parent using a strategy a great deal; the other not very much) in problem focused coping and symmetry in emotion-focused coping was found in an additional investigation of parents of pediatric cancer patients (Barbarin, Hughes & Chesler, 1985). Standardized questionnaires were used to examine the relationship between marital distress and coping in parents of pediatric cancer patients

in the 2 years following diagnosis (Dahlquist et al., 1996). These questionnaires measured the extent to which parents approached or avoided their child's illness. They found that greater use of problem-focused coping was associated with greater marital distress at diagnosis but not at follow-up. Furthermore, no association was found between marital distress and differences in coping behaviour within couples. A limitation of this study was that problem- focused coping was evaluated but emotion-focused strategies were not. Finally, marital satisfaction of parents of pediatric cancer patients was examined in relation to their psychological distress and coping preferences over a year. Fathers and mothers did not differ in their use of problem-focused and emotion-focused coping. A significant increase in marital dissatisfaction for the group as a whole was reported. This dissatisfaction was positively associated with psychological distress at 6 and 12 months. Paternal distress was related to individual coping style, whereas maternal distress was in response to partner's coping preferences. As well, it was noted that discrepancies in coping within couples were associated with marital distress in both partners. Also, a discrepancy in emotion-focused coping, was found as a risk factor for concurrent, longitudinal and prospective dissatisfaction in both partners in a marriage (Hoekstra-Weebers, Jaspers, Kamps & Klip, 1998a).

Pediatric Disability Literature

“The unexpected, irreversible and involuntary nature of events surrounding the birth of a child with a disability greatly increases a family’s vulnerability to stress and crisis” (Minnes, Nachshen & Woodford, 1999, p.159). Family reactions and responses to

childhood disability vary. Initial parental reactions to childhood disability include shock and disbelief, grief, tension, confusion, helplessness, anger, sorrow, frustration, anxiety and guilt (Minnes et al., 1999). It has been suggested that these reactions and the process of adjustment subsequent to the diagnosis of pediatric disability is similar to the stages of bereavement (Beresford, 1994; Minnes et al., 1999). Family expectations, dynamics and roles are all affected (Minnes, 1988; Minnes, McShane, Forkes, Green, Clement & Card, 1989; Minnes et al., 1999). Adaptation is viewed as an ongoing process, including periods of distress and adjustment (Minnes et al., 2000). The family's energy is directed primarily into caring for their special needs child (Beresford, 1994). Stressful situations are encountered, both related to the child's disability and other changes in family circumstances. The degree of adjustment and well-being of all of the family members are continually affected. Parents are required to deal with an ongoing, chronic situation involving a multitude of stressors arising from different situations and predicaments (Spinetta, 1981), including stresses associated with stigma, repeated disappointments, and burden of care (Beresford, 1994). For example, significant stages, defined by the child's chronological age, such as developmental milestones are often missed and expectations regarding the child's independence and maturity often become an increasing source of stress and anxiety for parents (Conoley & Sheridan, 1996; Lezak, 1987; Minnes et al., 1999).

The adjustment of parents of children with developmental disabilities is contingent upon numerous factors. They include, and are not limited to, the child's characteristics, family characteristics, family resources, and individual and family coping strategies (Conoley & Sheridan, 1996; Lezak, 1987; Minnes et al., 1999).

Coping with Pediatric Disability

The investigation of coping strategies utilized by parents of children with disabilities has primarily focused on determining the presence or absence of coping strategies, as well as identifying the most successful strategies according to parents (Beresford, 1994). As a result, a number of different strategies and taxonomies of coping in parents of children with disabilities have been documented (Beresford, 1984).

Coping patterns and concerns of mothers and fathers have been found to differ (Minnes, 1998). Fathers have often reported to respond less emotionally than mothers and have expressed more concerns about long-term financial and social dependency of the child, whereas mothers have tended to focus upon issues related to caring for the child and meeting the needs of the entire family (Minnes, 1998).

Problem-focused strategies were found to be the prominent type of strategies used by parents of children with disabilities in a study conducted by Bregman (1980). Emotion-focused strategies were identified as well, but were used less frequently in comparison to problem-focused coping (Bregman, 1980).

Parents of multiply disabled children reported using a combination of emotion-focused and problem-focused strategies (Brown & Hepple, 1989). Confronting the problem and restructuring the situation were the most commonly used strategies by the parents in the study (Brown & Hepple, 1989).

The coping strategies employed by parents of autistic children were examined in a study by Bristol (1984). Both problem-focused and emotion-focused strategies were used by parents. Strong beliefs and involvement in their child's care and rehabilitation were predominantly used by the parents (Bristol, 1984).

Coping strategies involving cognitive appraisal were associated with positive adaptation in mothers of children with disability (Affleck & Tennen, 1993). Various coping strategies were identified, however the prominent strategies included, obtaining a sense of meaning in their experiences with the child, having a sense of control and mastery, and using optimism.

Coping in parents of children with Fragile X syndrome, Down syndrome, developmental delay or other causes was investigated (Minnes & Nachshen, 1998). A combination of emotion-focused and problem-focused coping strategies were reported including persistence, focusing on the positive, information seeking and trusting one's own judgement.

Coping with Pediatric Disability and Parental Well-Being

Numerous studies have examined the affect of coping on the well-being of parents of children with pediatric disabilities.

Parents of children with disabilities who used problem-focused as opposed to emotion-focused coping strategies were found to report less stress and greater well-being

(Glidden, Kilpart, Willoughby & Bush, 1993; Shapiro, Blacher & Lopez, 1998). As well, parents who relied on themselves rather than others reported less depression than those who relied heavily on others (Glidden, Kilpart, Willoughby & Bush, 1993; Shapiro, Blacher & Lopez, 1998).

Quine & Paul (1991) explored coping strategies of mothers with children with severe learning disabilities. Use of emotion-focused coping was significantly related to poor adjustment. The amount and effectiveness of the mother's perceived coping skills were positively associated with adjustment.

Coping in mothers and fathers of children with Down's Syndrome was investigated in relation to physical and mental health and satisfaction with life (Sloper et al., 1991). The study incorporated an adapted version of the Ways of Coping Checklist (Lazarus & Folkman, 1980). A high use of problem-focused coping significantly predicted mother's perceived satisfaction with life. In comparison, an emotion-focused strategy, "wishful thinking" was a significant predictor of poor mental and physical health for the mothers. "Passive acceptance," an emotion-focused strategy, was negatively associated with perceived satisfaction with life for the fathers in the study. None of the coping strategies significantly predicted father's mental or physical health.

Thompson, Zeman, Fanurik & Sirotokin-Roses (1992) investigated coping styles in parents of children with Muscular Dystrophy. Parents with poor adjustment used more emotion-focused strategies than did parents with good adjustment scores. Parents with

poor adjustment scores also used a higher ratio of emotion-focused to problem-focused coping strategies.

Miller, Gordon, Daniele & Diller (1992) explored coping in mothers of physically disabled children using a revised version of Ways of Coping Questionnaire (Folkman & Lazarus, 1988). The use of emotion-focused strategies was positively associated with maternal distress. Problem-focused strategies were associated with lower distress in the mothers and included confrontative coping, problem-solving and seeking social support.

Statement of the Problem

According to Lazarus (1993), in the process of adaptation, the actual coping strategies that parents use to manage the stress of the diagnosis and the treatment of their child are important. Coping behavior may assume a mediating role between this stressful event and parental psychological functioning. The coping strategies of each parent are also likely to affect the marital relationship. Studies of parents of children with disabilities and chronic illness have investigated role strain, marital satisfaction and psychological distress. However, many of these studies have not focused on the context for coping, combining children with a wide range of ages, medical conditions and other circumstances. Another shortcoming of research on caregiving is the nearly exclusive focus on mothers. It is well known that childhood disability and chronic illness has an impact on all members of the family system, and that studying both parents is needed to fully understand the family environment (Taanila, Kokkonen & Jarvelin, 1996; Quittner

et al., 1998). The other main criticism of parental adjustment studies is their global level of measurement. Often the measures incorporated in the study are not specific enough or relevant to the caregiving context. Global measurement of constructs such as the presence of marital distress do not address its cause(s), nor its effects on daily life functioning of the family unit (Quittner et al., 1998). As a result, the relationships suggested between stress and psychological adaptation are difficult to interpret (Quittner et al., 1998). Future studies of parental coping, therefore, need to include: the investigation of both parents, the use of contextual settings and the ability to measure specific factors which affect coping strategies.

Adaptation to a stressful event, such as a disability, would be better understood by examining the specific context in which it occurs. Acquired brain injury provides a context for studying the coping process, as it has a definite onset, and is usually classified as a chronic illness. As well, the parents of a child with an ABI are large determinants of their child's health; financially, medically, and emotionally. To a large extent, family health and functioning are a repercussion of decisions and reactions employed by parents. Individual parental reactions also influence marital relations, thus affecting partner health. Despite the potentially important role of the family in the child's recovery, few investigators have attempted to assess family functioning following ABI (Wade et al., 1995). Parental reaction and adjustment generally have not been the focus of research or rehabilitation. Moreover, those studies of ABI that assessed family functioning have largely failed to employ validated measures of family status in a systematic, empirical study (Wade et al., 1995). At present, review papers suggest that there is a general

consensus among researchers that adaptive family coping leads to better adjustment following ABI (Max et al., 1998; Wade et al., 1996). However, in order to develop intervention strategies and techniques for use in rehabilitation therapy programs, a deeper understanding of coping strategies and family relationships is needed.

Paying close attention to parental coping strategies would provide clinicians with information and insights useful for anticipating and reducing the development of serious dysfunction within individual family members and the family system, which are unfortunately so common following ABI. Investigating coping strategies associated with adaptive adjustment following ABI could provide an empirical basis for the development of rehabilitation therapy programs focused on identifying limits of current coping and implementing appropriate intervention.

Purpose and Objectives

The purpose of this study was to enhance the understanding of the family environment following the acquired brain injury of a child, through the investigation of individual parental coping strategies, the relationship that exists between maternal and paternal coping strategies, and the relationship between parental coping and (a) social support, (b) the family environment.

The objectives of this study were:

- 1. to identify the prominent types of coping strategies used by parents of a child with an acquired brain injury: problem-focused, perception-focused or emotion-focused (Pearlin & Schooler, 1978);**
- 2. to determine the mechanism of the relationship (supplementary, complementary) between the coping strategies of parents of a child with an acquired brain injury; and**
- 3. to examine the extent to which social support and family environment affect parental coping.**

Research Design

A cross-sectional design was used in which 30 participants, corresponding to 15 families, were required to complete the Ways of Coping Scale (Folkman & Lazarus, 1988; revised McColl & Skinner, 1995b), the Types of Support Questionnaire (McColl & Skinner, 1995b) (based on the Interpersonal Support Evaluation List) (Cohen et al., 1985), and the Family Environment Scale (short version) (Moos, 1974). The participants were also asked to provide relevant demographic data pertaining to the objectives of the study.

Chapter 2: Literature Review

Coping

History

Research on coping began in the 1960s, when work being conducted on defense mechanisms started to coalesce under a “coping” label. The concept of coping began to acquire a technical meaning for some researchers, who labeled adaptive defense mechanisms as coping activities (Alker, 1968; Haan, 1963; Hunter & Goodstein, 1967; Kroeber, 1963). According to Haan (1965, p.374), “coping behaviour is distinguished from defensive behaviour since the latter by definition is rigid, compelled, reality distorting and undifferentiated, whereas the former is flexible, purposive, reality oriented, and differentiated.” Before this period, the word coping was used informally in the medical and social science literature (Lazarus, 1993; Lazarus et al, 1974; Lazarus & Launier, 1978; Roth & Cohen, 1986; White, 1974). Originally, coping provided a theme under which clinical description and evaluation were often organized (Lazarus & Folkman, 1984). Currently, coping has become a major topic of research interest in various subareas within psychology (e.g. personality and social psychology, health psychology, behavioural medicine) and in related fields such as psychiatry, social work, sociology, education and rehabilitation (Zeidner & Endler, 1996).

Definition

Coping is a term used widely in a colloquial sense, often relying on the context to explain what is meant (McHaffie, 1992). Studies on coping have only recently emerged

using concrete terminology (Schreurs & De Ridder, 1997). As a result, an abundance of definitions have surfaced over the past four decades. The definitions are mainly original taxonomies of coping and classifications of coping behaviours (Schreurs & De Ridder, 1997). Examples of such classifications include avoidance coping, approach coping, repression coping, escape coping and denial coping (Zeidner & Endler, 1996).

Coping is generally thought of as a multifaceted concept (McHaffie, 1992). However, almost all definitions of coping revolve around the notion of attempting to restore equilibrium in response to stress (Monat & Lazarus, 1985; Pearlin & Schooler, 1978; Weisman & Worden, 1976). The theoretical framework of this definition equates coping with adaptational success (Lazarus & Folkman, 1984). It has been suggested that coping and adaptation are distinct concepts, and that coping is “the process of coming to terms with a challenge and adaptation is the result” (Murphy, 1962, p.6). In 1978, Lazarus & Laurier challenged traditional definitions of coping and proposed a definition that emphasized coping as a response to psychological stress when resources are taxed or exceeded. Definitions supporting coping as a response are currently preferred by researchers (Endler & Parker, 1995; McHaffie, 1992; Zeidner & Endler, 1996).

In the most widely accepted definition, coping is conceptualized as an individual’s cognitive, affective, and behavioral attempts to reconcile a perceived discrepancy between situational demands and personal capacity or competence (Endler, 1988; Lazarus & Folkman, 1984). As such, coping is frequently seen as a “person variable,” occupying an important position, which mediates antecedent stressful events,

and such consequences as anxiety, psychological distress, and somatic complaints (Auerbach, 1989; Billings & Moos, 1981; Pearlin & Schooler, 1978). Coping is regarded as a regulatory operation, representing efforts to maintain a desirable level of personal functioning in the face of demands upon one's personal resources (Folkman & Lazarus, 1985). These demands have traditionally been studied in the form of environmental stimuli or stressors, such as life events, crises and hassles (e.g. Holmes & Rahe, 1967; Sarason, Johnson & Siegel, 1978) that require adjustment.

Functions of Coping

Coping functions refer to the purpose(s) which a strategy or style of coping serves (Lazarus & Folkman, 1984). A strategy is a scheme one adopts in order to cope with a stressful or taxing event (Lazarus & Folkman, 1984). Coping functions are defined based on the theoretical framework in which coping is conceptualized, and/or the context in which coping is examined (Lazarus & Folkman, 1984). Various coping functions have been identified in the literature over the past four decades.

According to an ego-psychology framework, White (1974, p.55) proposed that the functions of coping are: "a) to keep securing adequate information about the environment; b) to maintain satisfactory internal conditions both for action and processing information; and c) to maintain... autonomy or freedom of movement, freedom to use [one's] repertoire in a flexible fashion."

Mechanic (1974) proposed a social-psychology perspective of coping functions including: a) dealing with social and environmental demands; b) creating the motivation to meet those demands; and c) maintaining a state of psychological equilibrium in order to direct energy and skill toward external demands.

Pearlin and Schooler (1978) suggest that coping functions are exercised: to eliminate or modify conditions giving rise to problems; to perceptually control the meaning of experiences in a manner that neutralizes their problematic character; and to keep the emotional consequences of problems within manageable bounds.

Moos & Schaeffer (1986) suggest that when a major life event occurs, five tasks are encountered: establishing the meaning and understanding the personal significance of the situation; confronting the reality and responding to the requirements of the external situation; sustaining relationships with family members and other friends/individuals who may be helpful; preserving an emotional balance; and preserving a satisfactory self-image, whilst maintaining a sense of competence and mastery.

Theoretical Approaches to Coping

There have been three main theoretical approaches to the study of coping (Folkman & Lazarus, 1980; Menaghan, 1983). The first of these approaches conceptualizes coping in terms of a cognitive model, whereby realistic and flexible thoughts and acts are directed to solve problems and reduce stress (Lazarus & Folkman, 1984). The cognitive model views stress as a transaction between persons and the

environment. The perception of threat and its accompanying emotions necessitate coping efforts (Lazarus & Folkman, 1984). The second approach conceptualizes coping in a behavioural model. Coping is viewed as a series of acts that control aversive environmental conditions, thereby lowering the psychophysiological disturbance experienced (Lazarus & Folkman, 1984). The behavioural model of coping is based on the principals of behaviorism (Skinner, 1953). Coping behaviour is explained through the principals of social learning theory. Coping is learned through interactions between the individual and the environment. Stress is viewed as a stimulus event that presents difficult demands (Holmes, 1979; Homes & Rahe, 1967).

The main difference between the cognitive and behavioural approaches is the extent to which behaviour is emphasized (Lazarus & Folkman, 1984). The cognitive model focuses on perceiving and thinking about one's relationship with the environment, whereas the behavioural model is concerned primarily with overt, observable behaviour.

Four main limitations of these two traditional approaches of coping have been identified in the literature. The limitations include coping: seen as a trait or style; not distinguished from automatized adaptive behavior; confounded with outcome; and equated with mastery (Lazarus & Folkman, 1984; McHaffie, 1992; Zeidner & Endler, 1996).

Coping styles are referred to as broad, pervasive, encompassing ways of relating to situations (Lazarus & Folkman, 1984). Traits are properties one has that dispose them

to react in certain ways in a situation, and are usually narrow in scope (Lazarus & Folkman, 1984). It is presumed that traits are stable and operate the same way in all situations over the life course (Cohen & Lazarus, 1973; Lazarus & Folkman, 1984; Moos, 1974). This presumption underestimates the complexity and variability of actual coping efforts.

The distinction is often not made between automatized and effortful responses (Lazarus & Folkman, 1984). It is argued that automatic responses do not truly reflect the concept of coping (Lazarus & Folkman, 1984). If the response is automatic, it is not necessarily taxing to the individual and it does not exceed available resources. Coping, therefore, is not automatic; it is a purposeful process that requires effort (Murphy, 1974).

In both the cognitive and behavioural approaches, coping is equated with adaptational success (Lazarus & Folkman, 1984). This confounds the concept of coping during a situation with the outcome of the situation. If one has coped, it suggests that the demands of the situation were successfully overcome. If one did not cope, it infers ineffectiveness or inadequacy. However, coping can lead to positive and/or negative outcomes. Coping includes efforts to manage stressful demands regardless of outcome (Lazarus & Folkman, 1984).

Also implicit within these two approaches is the premise that some coping strategies are inherently better or more useful than others; that is, the best coping is that

which obviates the problem (Lazarus & Folkman, 1984). However, sources of stress such as natural disasters, inevitable losses, aging and disease cannot be mastered.

More recently, Lazarus & Folkman (1984) presented a third approach to coping theory based on a phenomenological transactional model of coping. The theory contends that stress is neither wholly in the environment nor wholly in the person but the product of the interplay between them both. It acknowledges aspects of persons, relationships of persons with others and with the total environment, the effect of specific stressful encounters and the fact that individual perception and appraisal changes over time and circumstance (Lazarus & Folkman, 1984). Coping is viewed as a dynamic process; it changes quality and intensity as the individual searches (Lazarus et al., 1974). The theory suggests that coping does not necessitate either a total triumph or total surrender, but rather a striving toward acceptable compromise (White, 1985). Coping efforts operate in one of three ways: directed towards the environment; towards the self; or in both directions (Lazarus & Launier, 1978); and can be best understood as the cognitive process of appraisal.

Appraisal is defined as a “judgement about the meaning or significance of a situation” (Cohen & Lazarus 1979; Lazarus, 1966). Cohen & Lazarus (1979) outlined two levels of appraisal: primary and secondary. A third level, denoted reappraisal, was added in 1984 (Lazarus & Folkman, 1984). Primary appraisal is a judgement about the significance of the event in terms of the well-being of the person. For example, “How much danger am I in from this situation.” Secondary appraisal involves the assessment

of what might/can be done to rectify the situation and the probable success rate. Tertiary appraisal refers to a change in the original perception of the event based on new information from the environment or from the person's own reactions. Thus, the appraisal process is cyclical and ongoing (McHaffie, 1992).

The appraisal process is influenced by many factors including the degree of threat, the stimulus and psychological variables. In terms of degree of threat, the closer in time to the anticipated encounter, the greater the threat. The character of the harmful agent, the viability of alternative routes to avoid harm, and constraints in the situation will all influence how the stimulus is appraised. Psychological variables, such as the perception of the event, also have an effect on appraisal. All three factors interact with value and belief systems; the more a person cares or is committed, the more vulnerable he is to a particular threat (Lazarus & Folkman, 1984).

Coping Assessment

The first generation of coping researchers shared a number of concerns that had a lasting impact on the coping area. Researchers began to identify and study a limited number of basic coping responses (Averill & Rosenn, 1972; Cohn & Lazarus, 1973; Kahn, Wolfe, Quinn, Snoek & Rosenthal, 1964; Lazarus et al., 1974; Pearlin & Schooler, 1978; Sidle et al., 1969). Two coping dimensions, in particular, were identified by researchers early on and have continued to attract much of the research attention: emotion-focused and problem-focused coping.

Problem-focused coping involves strategies that attempt to solve, reconceptualize and/or minimize the effects of a stressful situation. The emotion-focused coping dimension involves strategies that involve self-preoccupation, fantasy or other conscious activities related to affect regulation (for reviews see Lazarus & Folkman, 1984; Parker & Endler, 1992). Almost all coping measures developed in the past few decades include scales that assess these two coping dimensions (Billings & Moos, 1981; Carver, Scheir & Weintraub, 1989; Endler & Parker, 1990a, 1990b; Epstein & Meier, 1989; Folkman & Lazarus, 1980, 1985, 1988; Nowack, 1989; Patterson & McCubbin, 1987).

Avoidance-focused coping, another basic dimension identified by the first generation of coping researchers, has continued to generate considerable research attention (for reviews see Roth & Cohen, 1986; Suls & Fletcher, 1985). Depending on the theorist, the avoidance coping dimension has been conceptualized as involving person-oriented and/or task-oriented responses to effectively avoid the problem (Parker & Endler, 1992).

Pearlin & Schooler (1978) proposed a subdivision of the traditional category of emotion-focused coping, into two categories, namely emotion-focused and perception-focused. Perception-focused coping consists of cognitive attempts to control the meaning and interpretation of the distressful event after it occurs, but before the emergence of stress (Pearlin & Schooler, 1978). A distinction is made between the strategies that control the meaning of the situation (perception-focused) and those that control the emotional response itself (emotion-focused) (refer to Figure 1).

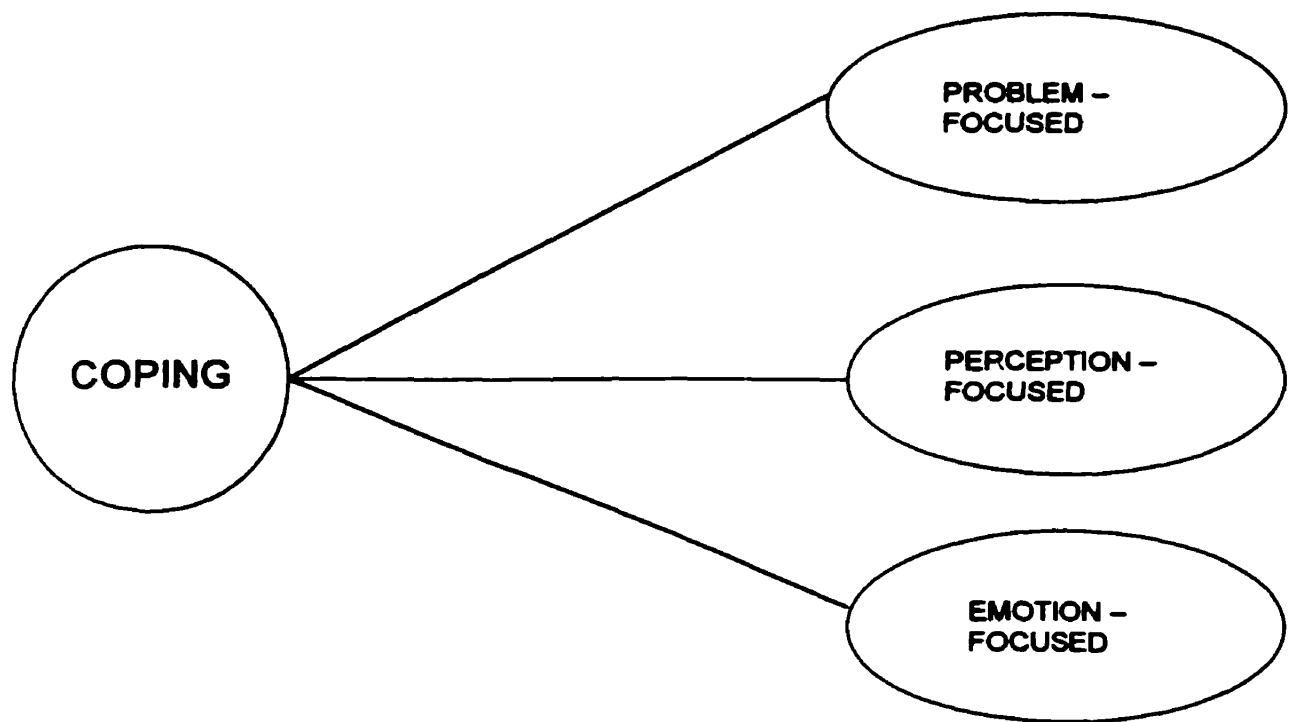


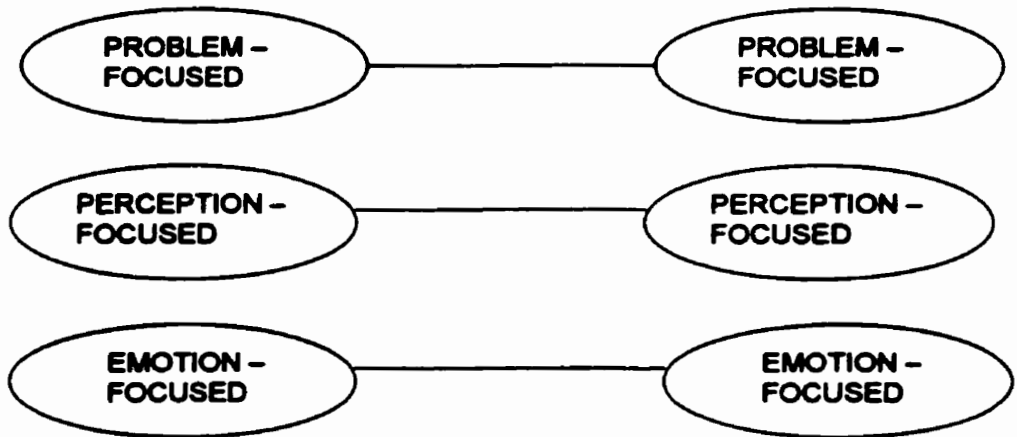
Figure 1: Coping Subscales (adapted from Pearlin & Schooler, 1978)

Of interest, is the nature of the relationship between the divisions of coping described by Pearlin & Schooler (1978) and individuals dealing with a specific situation. It might be that individuals respond using the same coping initiatives that others have employed when dealing with the same event. The relationship in which the utilization of similar coping strategies between individuals in the context of a specific situation is evident is defined as a supplementary relationship (McColl & Skinner, 1995b). As an example, both individuals may prefer to employ problem-focused coping strategies. The alternative conceptualization of the relationship between the coping divisions is one where others' coping is expected to fulfil the stress reduction functions that personal coping cannot. "It suggests that individuals are most responsive to those inputs from others that complement their own personal coping initiatives" (McColl & Skinner, 1995b). For example, an individual might use emotion-focused coping strategies, and rely on another individual to provide the perception and problem-focused strategies (refer to Figure 2).

Supplementary Coping

Maternal Coping

Paternal Coping



Complementary Coping

Maternal Coping

Paternal Coping

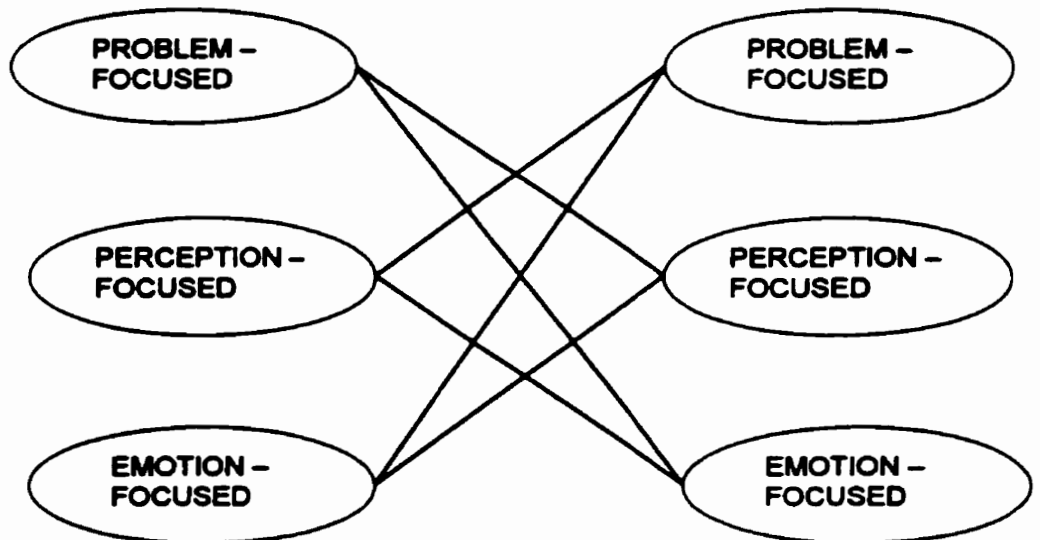


Figure 2: Supplementary versus Complementary Coping

Finally, when assessing coping strategies and functions, Folkman, Schaefer, & Lazarus (1979) highlight the importance of considering the extent to which an event is judged to be amenable to control. The effectiveness of a particular coping strategy is proposed to be dependent upon the match or goodness of fit between the strategy and the appraised controllability of the event. According to this “goodness of fit hypothesis,” the effectiveness of different coping strategies will vary as a function of the extent to which the event is appraised to be controllable. In controllable events, it is proposed that problem-focused coping will be adaptive, while a reliance on emotion coping is considered to be maladaptive. In contrast, for events appraised to be uncontrollable, a reverse pattern of results is predicted (Conway & Terry, 1992; Forsythe & Compas, 1987; Terry, 1994; Vitaliano, De Wolfe, Maiuro, Russo & Katon, 1990).

Conceptual issues in Coping Assessment

One of the most important distinctions in the coping area has been between measures that attempt to assess basic coping styles and measures that attempt to assess coping responses specific to a particular situation or problem (Endler & Parker, 1990b, 1993; Folkman, Lazarus, Dunker-Schetter, DeLongis & Gruen, 1986; Parker & Endler, 1992). This is sometimes referred to in the coping literature as the distinction between interindividual and intraindividual approaches to coping assessment (Endler & Parker, 1990a, 1990b; Parker & Endler, 1992), or dispositional and contextual approaches. This dichotomy is analogous to the distinction between state and trait variables commonly made in personality research (Endler, 1988).

The interindividual approach focuses on the identification and comparison of basic coping strategies or styles used by individuals across different types of stressful situations. It is assumed that people bring to a given context a relatively stable coping “disposition” (or trait) that is minimally influenced by situational contingencies. Carver, Scheier, and Weintraub (1989) have summarized this view: “people do not approach each coping context anew, but rather bring to bear a preferred set of coping strategies that remains relatively fixed across time and circumstances” (p. 270). Self-report measures taking this approach typically ask the individual how they generally react across stressful situations (Zeidner & Endler, 1996).

The intraindividual approach to coping assessment examines how coping behaviours change in response to particular or specific types of situations. According to this view, coping is a dynamic process, showing little consistency both across and within stressful situations (Folkman & Lazarus, 1980, 1985). Self-report measures taking this approach generally ask the individual to report how they reacted or responded to a specific context-based stressful situation (Zeidner & Endler, 1996). Some of these scales have been developed for use with a variety of stressful situations, while other scales were developed for use with specific health problems (for a review see Parker & Endler, 1992).

Contemporary theorists generally recognize that the interindividual and intraindividual approaches have complementary strengths in describing coping phenomena. Dispositional approaches tap generalizable, preferred coping styles that transcend particular situational influences (Epstein & Meier, 1989). Contextual

approaches reflect how a person copes with a particular type of stressful event and are responsive to changes in coping efforts during a stressful episode (Carver et al., 1989; Folkman, 1992).

Coping and Health Research

The 1990s have been concerned more than ever with the effects of psychosocial stressors on biological functioning. A relatively recent development has been the focus on coping processes. The relationship between health problems and coping has evolved into an important topic in the health psychology area (Auerbach, 1989; Endler & Parker, 1990b, 1993; Parker & Endler, 1992; Taylor, 1990). During this time, most researchers investigating coping have adopted a model that focuses on conscious processes or reactions to external stressful events (Endler & Parker, 1990b, 1993; Folkman & Lazarus, 1980, 1985, 1988; Krohne, 1988; Parker & Endler, 1992).

The study of coping reactions and strategies used in dealing with health problems has evolved into a major research area during the 1980s and 1990s (Auerbach, 1989; Endler, 1997; Endler & Parker, 1995; Endler, Parker & Summerfeldt, 1993; Endler, Parker & Summerfeldt, 1998; Parker & Endler, 1996). Parker (1996) in a content analysis of coping research published in the 1990s found that approximately 40% of empirical studies focused on the study of coping and health problems.

Interest in the link between coping style and health problems is part of a long tradition in the health psychology area (Taylor, 1990; 1995). In recent years, however,

much of the research on coping and health has used a situational approach (context specific) to coping (Endler & Parker 1995; Parker, 1996). Researchers have been particularly interested in studying the coping behaviors and strategies characteristic for specific health problems. As a consequence, a vast array of measures has appeared to assess coping responses to specific health problems. The proliferation of new coping scales for specific health problems has probably contributed to the growth of interest in the study of coping and health problems. It should be emphasized, however, that many of these scales have methodological weaknesses that limit their widespread use including: (a) many of the scales were created following simplistic test-development strategies (b) information on reliability and validity are frequently limited or nonexistent and (c) there has been inadequate sampling of coping items and populations (Endler & Parker, 1995; Oakland and Ostell, 1996; Parker and Endler, 1992).

In the current study, the process-oriented coping approach described by Lazarus & Folkman in 1988, was used. The functions of coping were defined by Pearlin & Schooler (1978) (Figure 1). Therefore, coping strategies were classified as problem-focused, perception-focused and emotion-focused. The relationship between maternal and paternal coping was also examined (Figure 2). An intraindividual, or state, approach to coping assessment was employed in the study. Coping was examined in response to a particular context.

Coping and Social Support

Social Support

Social support initially was examined in the mid 1970s to the early 1980s. At that time, social support was defined in concrete terms based on the interaction, person or relationship of interest (Veiel & Baumann, 1992). Over the past fifteen years, the term has become more abstract encompassing anticipation, perceptions, quality and quantity of support interactions (Hupcey, 1998; Veiel & Baumann, 1992).

Prominent Categories of Definitions of Social Support

A typical definition of social support would be, “the experience of being cared for and loved, valued and esteemed, and able to count on others should the need arise” (McCull, 1995a, p. 317). The majority of current definitions possess a common characteristic of a positive interaction or helpful behaviour provided to a person in need of support (Hupcey, 1998; McCull, 1995; Veiel & Baumann, 1992). Generally, the definitions of social support can fall into one of five categories. The first category, *type of support provided*, defines social support as the resources that are provided by other persons (Cohen, Mermelstein, Karmarck & Hoberman, 1985; Hilbert, 1990; Jacoboson, 1986; Lin, 1986; Pilisuk, 1982). For example, the provision of informational support, directed at altering the stressor itself, emotional support directed at altering the emotional response to the stressor, or instrumental support directed at altering the perception of the stressor are all classified as types of support (House, 1981). The *recipient's perceptions of support*, the second category, defines social support as the extent to which an individual believes that his/her needs for support, information and feedback are fulfilled

(Albrecht & Adelman, 1987; Heller, Swindle & Dusenbury, 1986; Procidano & Heller, 1983; Tilden, Nelson & May, 1990). The third category, *intentions or behaviours of the provider*, defines social support as an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient (Shumaker & Brownell, 1984; Thoits, 1985). *Reciprocal support*, the fourth category, defines social support as the actual giving, receiving and exchange of support. It is commonly referred to as the function of social support (Antonucci, 1985; Shumaker & Brownell, 1984; Vaux, 1992). The fifth category, *social networks*, defines social support as support accessible to an individual through social ties to other individuals, groups, and the larger community (Lin, Simeone, Ensel & Kuo, 1979; Thoits, 1982; Weiss, 1974).

Researchers have argued that the definition of social support should be viewed as a multifaceted concept, and therefore, should encompass at least three of the categories stated above instead of utilizing only one, which unfortunately, is common practice (Cohen & Syme, 1985; Hupcey, 1998).

Measures of Social Support

Although new measures of social support continue to be developed, the global categories studied are identical to those studied in the 1970s and 80s. The majority of the measures can be divided into one of three categories. *Network measures* focus on the individual's social integration into a group and the interconnectedness of those within that group. *Received support measures* focus on the amount of support the person

actually received or reported to have received. Lastly, the *perceived support measures* focus on the amount and type of support the person believes to be available if he/she should require it (Sarason, Sarason & Pierce, 1990). Limited studies examine the satisfaction with support, the reciprocity of support, the actual recipient needs or the negative aspects of support (Hupcey, 1998).

Social Support and Coping

At present, there is wide acceptance that social support and coping have independent effects on well being (Hupcey, 1998; Stewart et al., 1997). The integration of the perspectives of coping and social support may lead to a better understanding of the coping with a disability or a chronic illness, as well as the ways in which the social environment may be helpful or harmful in adapting to disability or chronic illness. Past thinking has alluded to a circular relation between coping and social support, suggesting a positive relationship. That is, the more adaptive coping, the better the social support or the greater the social support, the better the coping strategies. However, since negative social support is now an issue, this relationship is undergoing scrutiny (Hupcey, 1998; Stewart et al., 1997). Few studies have dealt with the relationship between coping and social support explicitly. An analysis of the literature suggests four theories explaining the mechanics of the relationship between social support and coping: *seeking social support as a coping strategy* (Heller & Swindle, 1983; Lazarus & Folkman, 1984); *social support as a coping resource* (Holohan & Moos, 1987, 1990, 1991; Thoits, 1986); *social support as dependent on the way individuals cope* (Sarason et al., 1990; Vaux, 1990); and *coping by a social system* (Shreurs & de Ridder, 1997). The first theory suggests that

part of the coping process is to seek social support (Heller & Swindle, 1983; Lazarus & Folkman, 1984). This view is best known in the literature, and as a result it is most often measured. Many coping questionnaires include social support as a coping strategy. Some researchers suggest that social support is one of the most important dimensions in understanding coping (Heller & Swindle, 1983; Lazarus & Folkman, 1984). According to Heller & Swindle (1993), the perception of the availability of social support is viewed as part of the secondary appraisal in which the individual appraises his/her possibilities for action which may or may not result in social support seeking behaviour.

The second theory suggests that social support is considered a coping resource (Holohan & Moos, 1987, 1990, 1991; Thoits, 1986). The social support network of the individual is already in place before the coping process begins, and is accessed as a resource for the individual during the coping process. The social environment may influence both the actual choice of a specific coping strategy and the skill in which this strategy is performed (Holohan & Moos, 1987, 1990, 1991; Thoits, 1986). This theory allows for the measurement of negative social support. Thoits (1986) stated that when coping, the social environment may help the individual to cope, and that the use of social support resources generally contributes to more adaptive coping strategies.

In the third theory, social support is considered dependent on the way individuals cope (Sarason et al., 1990; Vaux, 1990). The amount of social support received is a consequence of how an individual deals with stress. If an individual requests support, they will receive it. The way people cope, that is the coping strategies they employ,

determines the support they will be able to elicit from others in the future. This theory also allows for the measurement of negative support. For example, an individual with a disability is faced with the dilemma what extent he/she should present him/herself to others as a “victim.” If they wish not to be a burden to others, a solution would be to present themselves as coping efficiently on their own. If, on the other hand, they wish support, they will present themselves as needing help to varying extents.

The last theory suggests that the relationship between coping and social support exists in coping through a social system (Shreurs & de Ridder, 1997). All of the other theories view social support and coping as two independent constructs that are correlated in some manner. This theory, however, puts forth that the two constructs are integrated; that is, they necessarily exist at the same time. The theory is in its infancy, and as a result, studies have not yet examined the proposed relationship. It has been suggested that by studying the phenomena of social support and coping in intimate relationships, such as family coping and spousal relationships, this theory may be developed.

The present study utilized a perceived support measure (Sarason, Sarason & Pierce, 1990) to investigate social support. The theoretical framework incorporated into the study was based on the view that social support is a coping resource (Holohan & Moos, 1987, 1990, 1991; Thoits, 1986), and the dimensions of social support were instrumental, informational and emotional support as defined by House, in 1981.

Coping Following Pediatric Acquired Brain Injury (ABI)

Pediatric Acquired Brain Injury

Pediatric acquired brain injury (ABI) is defined in this study as damage to the brain that occurs after birth and before 19 years of age, and is not related to a congenital neuro-developmental disorder. The damage may be caused by a traumatic injury to the head resulting from, for example, a motor vehicle accident, or a non-traumatic injury such as a stroke. Traumatic brain injury, (TBI), typically results from a blow to the cranium or a rapid acceleration/deceleration and rotation of the head, with or without a blow to the cranium (Zink, 1996). Traumatic brain injury is classified as either open or closed head injury (Engberg, 1995). Open head injuries are the result of penetration of the skull. The vast majority of head injuries, however, are classified as closed head injuries (CHI), wherein the skull is not actually penetrated (Whyte & Rosenthal, 1993). TBI is not usually an isolated injury; often, there is also serious injury to other organ systems (Zink, 1996). Non-traumatic brain injury does not result from acceleration/deceleration and rotation of the head, but rather an abnormality in the brain, due to a growth, a ruptured vessel, or inhalation of foreign substances (Provincial Report, 1999). With non-traumatic injuries, the presence of injury to other organ systems is rare (Provincial Report, 1999).

Incidence in Children

Acquired brain injury is a significant cause of morbidity and mortality in children (Provincial Report, 1999; Wade, Taylor, Drotar, Stancin & Yeates, 1996; Watt, 1999). The incidence of childhood brain injury is approximately 219.4 per 100 000 per year. It

is estimated that 185 per 100 000 children between the ages of 0-14, and 295 per 100 000 adolescents and adults falling in the age range of 15-24, are hospitalized annually for brain injury (Provincial Report, 1999; Watt, 1999). However, it has been suggested that the reported incidence rates of ABI are highly underestimated; that, reporting by families and professionals is thought to be much lower than what is actually the case, resulting in ABI being termed a “silent epidemic” (Waaland & Kreutzer, 1988).

Etiology

Two peak periods of incidence of childhood ABI are reported in the literature, early childhood (less than 5 years of age) and mid-to-late adolescence. The incidence of ABI is higher among males, ranging 2-4:1, and also more prevalent amongst the lower socio-economic class (Luerssen, Klauber & Marshall, 1988). Age dependent factors, inherent susceptibility of the brain, and regenerative mechanisms can all impact on mortality and the extent of the severity of the resultant ABI. The very young developing brain is particularly susceptible to extensive damage and, as a result, has a higher likelihood of incurring severe damage (Bruce, Schut & Bruno, 1978; Graham, Ford & Adams, 1988; Graham, Lawrence & Adams, 1988). It has also been reported that children who sustain an ABI exhibit greater levels of preinjury impulsivity, attention-seeking behaviour, and aggression (Rutter, Chadwick & Shaffer, 1980).

Mechanism of Injury

The mechanism of injury for TBI is most often motor vehicle related. The percentage of motor vehicle and motor vehicle related accidents increases with age.

Approximated 20% of TBIs in children ages 0-4, and 66% percent in adolescents result from motor vehicle accidents (Levin, Aldrich & Saydjari, 1992). Younger children more commonly suffer pedestrian or bicycle-related injuries, whereas adolescents are more often injured in motor vehicle accidents as passengers, similar to adults (Levin, Aldrich & Saydjari, 1992). Children under 5 years of age are at greatest risk to be injured by falls or parental abuse (Klauber, Barrett-Connor & Marshall, 1981), accounting of nearly 50% percent of all cases (Kraus, Fife & Cornroy, 1987; Levin, Aldrich & Saydjari, 1992; Luerssen, Klauber & Marshall, 1988). In contrast, sports-related injuries, as well as pedestrian, bicycle and motor vehicle accidents predominate the 5 to 14 year old range (Klauber, Barrett-Connor & Marshall, 1981; Kraus, Fife & Cornroy, 1987; Levin, Aldrich & Saydjari, 1992; Luerssen, Klauber & Marshall, 1988). In contrast, the most common causes of non-traumatic ABI in children include: cerebrovascular accidents (stroke), tumours, aneurysm, anoxia, viral infection (such as meningitis or encephalitis), and forms of substance abuse (includes gasoline or glue sniffing). The incidence of childhood stroke and viral infection is higher in relation to the other causes of non-traumatic ABI. The statistics for the mechanisms of non-traumatic ABI are not as well documented in the literature, as approximately only 10% of all ABI cases are due to non-traumatic injuries.

Impairment

Acquired brain injury results in a wide range of cognitive and behavioural sequelae (Wade, Taylor, Drotar, Stancin & Yeates, 1996). The individualized pattern of

impairment is based on the severity of injury, the nature of the brain damage, and the associated medical conditions (Whyte & Rosenthal, 1993).

The most prevalent deficits affect the areas of intelligence, adaptive reasoning, memory, behavior, emotion, psychomotor, motor, academic performance and social competence (Provincial Report, 1999). Cognitive deficits are often different and more severe in childhood, compared to similar trauma in adulthood (Ewing-Cobbs & Fletcher, 1987; Ewing-Cobbs, Fletcher & Levin, 1986; Rutter, Chadwick & Shaffer, 1983). Expressive language and motor functions are particularly vulnerable under age 6 (Ewing-Cobbs & Fletcher, 1987). Immature neuroanatomy often accounts for these differences. As well, children may “grow into” deficits as developmental demands for verbal encoding, fluent language, and higher-level reasoning increase (Black, Blumer & Wellner, 1971). Changes in behaviour, mood (emotionality), and personality after ABI have been documented by many investigators and are considered by clinicians to be among the most difficult to effectively manage (Kaitaro, Koskinen & Kaipio, 1995).

Psychiatric disorders in children and adolescents are most common after TBI, when compared with non-traumatic ABI, especially after severe traumatic brain injury (Max, Koele, Smith, Sato, Lindgren, Robin et al., 1998). Severe TBI has been associated with a significantly higher rate of novel psychiatric disorders compared with children with mild TBI and orthopedic injury (Max, Koele, Smith, Sato, Lindgren, Robin et al., 1998).

Outcome

Appropriate aggressive management of children with head injuries in the acute setting has led to decreased mortality and morbidity and improved functional outcomes (Muizelaar, Marmarou & Ward, 1991). Although most of the children hospitalized for ABI each year enjoy substantial recovery, those with moderate to severe injuries are at marked risk for ongoing neuropsychological, behavioural, and academic problems (Wade, Taylor, Drotar & Stancin, 1995). Approximately 21% of acquired brain injuries require a certain amount of post-acute rehabilitation services on an inpatient/outpatient, and in-home basis (Provincial Report, 1999). Most individuals need long-term follow up, specialized rehabilitation and support services, as the natural growth and development of the child is hindered by the chronicity of ABI, and the child requires special assistance to maintain developmental levels both academically and socially (peers and family) (Provincial Report, 1999).

Family Reactions to Pediatric Acquired Brain Injury

A review of current literature suggests that the family has a major role in the child's eventual adjustment to his/her acquired brain injury (Kreutzer, Marwitz & Kepler, 1992; Rivara, Jaffe, Fay, Pollisar, Martin, Shurtleff & Liao, 1993; Testani-Dufour, Chappel-Aiken & Gueldner, 1992). Families play an integral role in the child's recovery process. The scope of the ABI experience encompasses the whole family. Attention to the individual family system is necessary in order to enhance the recovery of the entire family unit (Testani-Dufour, Chappel-Aiken & Gueldner, 1992). Treating the child is only one component of a comprehensive recovery program (Conoley & Sheridan, 1996).

ABI in children is likely to affect families in many important ways, especially given the marked risk of ongoing neuropsychological, behavioural, and academic problems in these children (Wade et al., 1995). Relatively little research has concentrated on the long-term impact of this disability on the family members (Florian, Katz & Lahav, 1991). With the immediate focus on the patient and their needs, the family's needs may go unnoticed or unrecognized (Testani-Dufour, Chappel-Aiken & Gueldner, 1992). Professionals need to understand the emotional impact and the unique grieving patterns of the family (Testani-Dufour et al., 1992).

Following childhood ABI, families experience a dramatic swing of emotions, from fear to happiness, bewilderment to anger, discouragement and depression, mourning, and finally (it is hoped), reorganization. For a family to accept the possibility that their child may remain forever childlike and/or different from their premorbid personality is a very difficult concept to grasp. The family may have to shift their expectations from hopes of full recovery, to accepting that little or no change is likely. The dreams parents associate with their children may have to give way to new goals that involve a lifetime of dependency on the part of the survivor (Conoley & Sheridan, 1996).

Injury related burden, reported by families, is closely tied to injury severity and encompasses stresses associated with medical management, disruption in family routines, changes in the injured child's behaviour, and concerns over the reactions of other family members (Conoley & Sheridan, 1996; Wade et al., 1995). The tasks and stresses associated with an acute hospitalization of a family member are quite different from those

arising from chronic neuropsychological and behavioral deficits (Rollan, 1987). As well, children who incur acquired brain injuries are more likely to have preexisting behavioural problems and come from dysfunctional families than children with chronic illnesses (Bijur, Haslum & Golding, 1990). Childhood ABI victims exhibit greater levels of preinjury impulsivity, attention-seeking behaviour, and aggression (Miller, 1991). Following the injury, cognitive and behavioural dysfunction, such as emotional disinhibition, impulsivity, and failure to learn from experience, place significant demands on parents to alter expectations, rules, and disciplinary practices (Lezak, 1987). Although children are predictably dependent and require consistency and limit setting, expectations regarding the child's level of independence and maturity may become an increasing source of stress and anxiety as the child grows older (Lezak, 1987). Unfortunately, all too often the grieving process occurs again and again, usually after the child misses a developmental or social milestone (Conoley & Sheridan, 1996).

According to Lezak, (1986), the behaviors of children with head injuries that are most likely to cause problems for family members include impaired social perceptions and awareness, impaired control, dependency, and inability to learn from experience. Indirect consequences that affect the family include the injured individual's feelings of anxiety, paranoia, and depression. A number of investigators have speculated that the initial cognitive impairments and behavior changes in the child disrupt family life and adversely affect parent adjustment and parent-child interactions (Boll, 1983; Brooks, 1991; Brown, Chadwick, Schaffer, Rutter & Traub, 1981; Fletcher, Ewing-Cobbs, Miner, Levin & Einsenberg, 1990; Perrott, Taylor & Montes, 1991). These changes may

negatively affect the child's subsequent psychological adjustment, in spite of cognitive recovery.

Adaptation, including parental psychological adjustment, marital quality, and family functioning, reflect the family's ability to respond and cope with the burdens of the injury as well as with the preexisting stresses and strains (Wade et al., 1995). Family coping resources are taxed because they must attempt to accomplish a wide array of tasks (Bragg, Klockars & Berninger, 1992). Coping with the impact of brain injury is described in the medical and rehabilitation literature as one of the most difficult tasks, which may confront a family (Bond & Miller, 1983; Oddy, 1984; Rosenthal, Griffith, Stolov, Clowers, 1981). Primary caregivers usually have elevated levels of stress and depression. As well, caregiver distress has been shown to increase over time (Brooks, 1991; Livingston, Brooks & Bond, 1985; Oddy, Humphrey & Uttley, 1978; Rosenbaum & Najenson, 1976).

Siblings of children with ABI are also affected in numerous ways following the injury. Often, they may vie for some of the attention lavished on the survivor (Dyson, Edgar & Crnic, 1989). It has also been shown that siblings of children with ABI are at risk for developing behavioural problems (Breslau, 1982), anxiety (Breslau, 1983), social withdrawal (Lavigne & Ryan, 1979), feelings of guilt and anger (Chinitz, 1981), reduced self-esteem (Ferrari, 1984) and feelings of inferiority (Taylor, 1980). Interestingly, as siblings grow older they report realizing that the burden of care may fall upon them, which is often both anxiety and anger producing (Conoley & Sheridan, 1996).

Coping Following Childhood ABI

The literature published since 1975 on the effects of pediatric ABI on family coping and functioning reveals that few systematic, hypothesis-driven investigations have been conducted (Wade et al., 1995). Various retrospective studies were completed, however. Parental anxiety, changes in parent-child relationships, and marital tensions were found in response to posttraumatic behaviour problems associated with the child survivor (Rutter et al., 1983). Another preliminary study suggested that the severity of the TBI was correlated with psychological distress in the primary caregiver, and with perceived marital tension and strain (Harris, Schwaitzberg, Seman & Herman, 1989). Higher levels of self-reported stress associated with parenting of the children with TBI, than in the siblings, was reported by Perrott, Taylor & Montes (1991). Beyond these empirical studies, clinical reports have described family stress arising from a lack of information about ABI, limited support and remediation services, increased burden of care, and fears about the child's ability to function in the future (Waland & Kreutzer, 1988). It has also been shown that family stress arising from ABI may be associated with organizational difficulties, impaired family communication and supportiveness, adjustment problems in siblings, and restrictions in social activities and interactions with friends (Brooks, 1991; DePompei & Zarski, 1989; Rivara, 1994). However, not all families are adversely affected. Some families appear to draw closer together as a result of the crisis. Clinical impressions indicate that intact and communicative families may be able to cope more effectively with the trauma of the injury, than families in which there are higher levels of preexisting stress or less cohesiveness (DePompei & Zarski, 1989; Rivara, 1994).

In a study by Koseiulek, (1997), manageability accounted for a large amount of the variance in family adaptation. The findings suggest that family adaptation to brain injury may be largely influenced by a family's view of the controllability of the brain injury situation. Families assess the degree of controllability of the injury, the amount of change expected of the family system, and whether or not the family is capable of responding effectively to the situation. According to the goodness of fit hypothesis (Folkman, Schaefer, & Lazarus, 1979), the effectiveness of different coping strategies will vary as a function of the extent to which the event is appraised to be controllable. In controllable events, it is proposed that problem-focused coping will be adaptive, while a reliance on emotion-focused coping is considered to be maladaptive. In contrast, for events appraised to be uncontrollable, a reverse pattern of results is predicted (Conway & Terry, 1992; Forsythe & Compas, 1987; Vitaliano, De Wolfe, Maiuro, Russo & Katon, 1990; Terry, 1994). McCubbin and colleagues (1993) suggest that those families effective in managing tension by placing problems and difficulties in a more manageable form through active problem solving will adapt more successfully to major stressors such as brain injury. Meaningfulness was also predictive of family adaptation (Koseiulek, 1997). The difference between events that lead to dysfunction and those that lead to successful coping depends upon the family's interpretation of the event. Positive appraisal involves the family redefinition of stressful events to make them more meaningful. In the face of brain injury, the family is called upon to appraise its past and future in an attempt to give meaning to the injury and the resulting changes in the family system needed to facilitate adaptation. It was suggested that the family that views a brain injury as a manageable family challenge will most likely adapt more successfully than a

family that views the brain injury as catastrophic. Thus, families that utilize perception-focused coping strategies, aimed at altering the meaning of the ABI, may adapt more successfully to the outcomes of the ABI than families who do not.

Up until 1996, only two studies investigating family functioning following onset of pediatric ABI were neither retrospective nor a reliance on clinical observation to the exclusion of empirically valid measures (Wade, Taylor, Drotar, Stancin & Yeates, 1996; Rivara, Jaffe, Polissar, Fay, Liao & Martin, 1996). The findings of a 3-year prospective study examining the predictors of family outcome following childhood TBI were reported by Rivara and colleagues, in 1996. It was found that preinjury functioning was the best predictor of 3-year outcomes. Fewer changes in family functioning were reported over 3 years in the mild or moderate TBI groups, whereas more deterioration occurred in the severe group. At 3 years, one third to one half of parents in either the moderate or severe groups reported medium to high strain. Low levels of family control and high levels of expressiveness correlated more strongly with better outcomes for severe group. Positive change for the severe group was marked by better preinjury levels of communication, expressiveness, problem solving, use of resources, role flexibility, greater activity orientation, and less conflict, control and stress (Rivara et al., 1996).

The second prospective study by Wade et al. (1996), reported that families of children with TBI experienced a significant amount of injury related stress, and that the parents of the children with TBI also had higher levels of psychological symptoms, when compared with parents of children with orthopedic injuries (Wade et al., 1996). The

study also indicated that family roles, responsibilities, and interactions may be altered, with adverse consequences for siblings (Wade et al., 1996).

Family Outcome

Outcomes for families vary. As stated above, the premorbid functioning of the family is a strong predictor of its members' success in coping with their ABI survivor. Well-functioning families are especially helpful in promoting growth in the survivor's emotional and behavioural skills (Rivara, Jaffe, Fay, Pollisar, Martin, Shurtleff & Liao, 1993). A family's ability to successfully cope with the initial demands of the injury may have important implications for longer-term family adaptation (Wade et al., 1996). Families facing multiple stressors in addition to the injury, and those who cope poorly may be at greater risk for adverse consequences (Wade et al., 1996). Suggested moderators of successful adaptation are: expressiveness, flexibility, social support, family cohesion, and a positive outlook (Rivara et al., 1996). Fortunately, some families succeed in obtaining an optimal outcome. Others are not so fortunate. At present, negative outcomes resulting in divorce, family conflict, substance abuse, and social isolation are far too common, and need to be addressed (Conoley & Sheridan, 1996).

Rationale

This study was designed to contribute new information about the social environment affecting adaptation and adjustment for children with disabilities. The environment is dynamic, and can have an enabling or constraining effect on the performance and health of a child (Law et al., 1997).

The health problems that accompany the ABI themselves are stressors that place demands on multiple interacting systems: 1) physiological resources (e.g. recovery and resistance in the face of a taxed immune system) 2) behavioral practices (e.g. abandoning toxic habits, complying with a treatment programme) 3) psychological reactions (e.g. dysphoric reactions to perceived loss of autonomy or changes in self-image) 4) social resources (e.g. the availability of support systems and one's capacity to cultivate and make use of them) (Parker & Endler, 1992). The child with an ABI must face all of these stressors, along with the stresses of being integrated back into the family environment.

The family environment, which is largely determined by the parents will therefore influence the adaptation and adjustment of the child with brain injury within it. Day to day functioning is affected. Children with ABI need high levels of attention from their parents, and parents have a continuous concern for the well-being and future of their children. Parental coping strategies enable or hinder child adjustment and adaptation to ABI. By understanding the reactions of parents to a child's ABI, the opportunity to better understand the family environment experienced by the child is presented. Parents need to help the child accept their ABI and need to succeed in aiding the child to cope with the realities of the disability, while encouraging the child to develop as normally as possible (Taanila, et al., 1996). To the extent that parental coping is successful and compatible, the social environment of the home will be experienced as enabling the child's adjustment. To the extent that parental coping is unsuccessful and/or antagonistic, the environment will hinder adjustment. If maladaptive coping strategies are identified, rehabilitation therapy can help parents to capitalize on their strengths, and increase

adaptive coping strategies. This process will positively modify the environment, thus enabling adaptation and adjustment for the child.

Chapter 3: Methodology

Purpose

The purpose of this study was to enhance the understanding of the family environment following acquired brain injury of a child, through the investigation of individual parental coping strategies, the relationship that exists between maternal and paternal coping strategies, and the relationships between parental coping and (a) social support and (b) the family environment.

The objectives of this study were:

1. To identify the prominent types of coping strategies used by parents of a child with an acquired brain injury: problem-oriented, perception-oriented or emotion-oriented (Figure 1).
2. To determine the relationship (supplementary, complementary) between the coping strategies of parents of a child with an acquired brain injury (Figure 2).
3. To examine the extent to which social support and family environment affect parental coping.

Research Design

A cross-sectional design was used to investigate parental coping following onset of childhood ABI. Data were collected once from each participant. Data collection

occurred within two-years from the onset of the acquired brain injury. In this study, a cross-sectional methodology was used to: confirm ABI as a valid context for studying coping, identify factors which affect coping, and provide support for further examination of coping strategies, including longitudinal investigation. This was a non-experimental study, as there was no manipulation of the independent variable, and participants were chosen on the basis of the presence of their child's acquired brain injury.

Operational Definitions

Stressor (Lepore & Evans, 1996)

Stressor - refers to any environmental conditions that the participant would perceive as actually or potentially threatening, damaging, harmful, or depriving

Coping Strategies (Pearlin & Schooler, 1978)

Problem-focused - coping strategies that are directed at altering the stressor itself

Perception-focused - coping strategies that are directed at altering the perception of the stressor

Emotion-focused - coping strategies that are aimed at altering the emotional response to the stressor

Relationship between Parental Coping Strategies (McColl & Skinner, 1995)

Supplementary - both parents utilize the same type(s) of coping strategies

Complementary - parents utilize different coping strategies, and a balance of all three strategies is evident

Social Support (House, 1981)

Instrumental - supports that directly address the source of the stressor

Emotional - supports directed at moderating the emotional reaction to the stressor

Informational - advice, guidance and information that alters the perspective of the stressor

Severity of Injury - Coma depth is an index of severity that has been operationally defined and quantified by the Glasgow Coma Scale (Teasdale & Jennet, 1974). Eye opening, motor response and verbal response are rated on separate scales, the combined score of which will fall between 3 and 15. A score between 3 to 8 is indicative of severe brain injury, 9 to 12 of moderate injury and 13 to 15 of mild injury (Whyte & Rosenthal, 1993).

Marital Satisfaction - indication of contentment with partner relationship (global measure), on a likert scale ranging from 1- very unsatisfied to 10 - very satisfied.

Sample

Participants

The sample was composed of parents of children with a mild, moderate or severe acquired brain injury, as indicated by the Glasgow Coma Scale (GCS). Participants were recruited from two centres in the province: Bloorview MacMillan Centre (Toronto, Ontario); and The Child Development Centre, (Kingston, Ontario).

Inclusion Criteria

Participants were included in the study if:

1. their child had sustained an acquired brain injury within the past two years;

2. two parents were living with the child (not necessarily the biological parents), and had lived with the child since the onset of the injury;
3. the child was 18 years of age or younger at the onset of their acquired brain injury;
4. both parents were willing to participate in the study.

Exclusion Criteria

Participants were excluded from the study if:

1. the child had survived more than one incident of acquired brain injury;
2. one or both parents were not fluent in English.

Participant Demographics

The participants consisted of 15 families, and correspondingly, 30 parents of children who had sustained an acquired brain injury within two years of the study. Two families were recruited through the Child Development Centre (CDC) in Kingston, Ontario. Twenty-five families in which a child had experienced an ABI within the time frame of two years were identified by the CDC. Of those 25, only 5 families had 2 parents (not necessarily biological) living with the child, qualifying for the study. Two families participated and 3 did not respond or could not be reached. The remaining 13 families were recruited through Bloorview MacMillan Childrens Centre (BMC) in Toronto, Ontario. Of the 56 families identified by Bloorview MacMillan Centre, 21 families did not respond or could not be reached, 10 declined, 12 were single-parent families, and 13 participated.

Half of the 30 participants were male (fathers) and half were female (mothers). Only 2 of the 30 participants were not the biological parents of the corresponding child with an ABI. All 15 partnerships were legal marriages, heterosexual in nature.

The average age of the participant group was 39.23 years with a standard deviation of 5.26 years, and a range from 30 years to 53 years of age (refer to Table 1). Sixteen of the 30 participants were between the ages of 37 and 40. The average age of the mothers was 37.80 years with a standard deviation of 5.13 years. In comparison, the average age of the fathers in the participant group was 40.67 years with a standard deviation of 5.15 years.

The majority of the participants had post-secondary education. Over half of the 30 participants (73%) had acquired either a college diploma or a university undergraduate degree. All of the fathers participating in the study were employed in full-time positions. Twelve out of the 15 mothers were employed at the time of the study, in either full-time or part-time positions.

The average length of the partner relationship was 14.87 years with a standard deviation of 4.64 years, and a range of 6 to 22 years. As a large proportion (>50%) of the relationships were over 14 years in length, the effects of adjusting to a partner relationship were not considered in the study. The average satisfaction rating for the participant partner relationships was a 9, indicative of a high satisfaction level, on a scale

from 1 to 10, with 1 being very unsatisfied and 10 being very satisfied. The standard deviation was 1.34, and the range was from 5 to 10.

The combined income reported for 4 households was between \$25 000 – 50 000 dollars. The remaining 11 families reported a combined income of \$50 000+ dollars. Thus, the socio-economic status of the greater amount of families participating in the study is indicative of a middle-class population (Statistics Canada, 1998).

Table 1: Demographic Features of the Sample

Variable	n	%
Gender Parent		
Father	15	50
Mother	15	50
Age Parent (years)		
30 – 35	5	16.7
36 – 40	17	56.6
41 – 45	5	16.7
>45	3	10.0
Partner Relationship (years)		
06 – 10	4	13.3
11 – 15	14	46.7
16 – 20	8	26.7
>20	4	13.3
Education		
High school	8	26.7
College Diploma	9	30.0
Bachelor degree	10	33.3
Masters degree	3	10.0
Employment Status		
Employed	27	90.0
Unemployed	3	10.0
Economic Status		
\$0 – 25 000	0	0.0
\$25 – 000 – 50 000	8	26.7
\$50 000+	22	73.3

Demographic Profile for the Children with ABI

Of the children with acquired brain injuries corresponding to the 15 participating families, 12 were male and 3 were female (refer to Table 2). The resultant ratio of 4:1 males to females is consistent with the literature, which indicates that ABI is higher among males, ranging 2-4: 1 (Luerseen, Klauber & Marshall, 1988).

The average age of the children with ABI was 8.67 years, with a standard deviation of 5.42 years, and a range of 16 years, from 2 to 18 years of age. Slightly over 65% of the children were 2 to 8 years of age, and the remaining children were between 12 to 18 years of age. These two age groups were consistent with the two peak periods of incidence of childhood ABI reported in the literature, early childhood (less than 5 years of age) and mid-to-late adolescence.

The mean education level was 4.20 years, with a standard deviation of 4.51 years, and a range of 13, from 0 to 13 years of schooling. The majority of the children were attending school at the appropriate level for their age. Only a small percentage (14%) of the children were attending at a lower than normal education level for their age group.

The average time that had elapsed from the onset of the acquired brain injury for the children in the study was 19.93 months, with a standard deviation of 3.95 months, and a range of 16 months, from 8 to 24 months post-injury. Over half of the 15 children were

between 19 and 21 months post-injury. The majority of the families, therefore, were coping with a family member with ABI who was approximately 1.5+ years post-injury.

With respect to the cause of the acquired brain injury, 60% or 9/15 children sustained a traumatic brain injury, and 40% or 6/15 children sustained a non-traumatic brain injury. The etiologies of the traumatic brain injuries included 2 motor vehicle accidents, 4 falls, 2 assaults and 1 sports - related injury. The etiologies for the non-traumatic brain injuries consisted of 3 cases of viral infection, including encephalitis and meningitis and 3 cardiovascular accidents (stroke). All etiologies are consistent with the primary mechanisms of injury for acquired brain injury in the literature.

Table 2: Demographic Features of the Children

Variable	n	%
Gender Child		
Male	12	80.0
Female	3	20.0
Age Child (years)		
<4	2	13.3
04-08	8	53.3
09-12	1	06.7
13-18	4	26.7
Education (years)		
<1	4	26.7
01 – 04	6	40.0
05 – 09	2	13.3
10 – 13	3	20.0
Etiology of Injury		
<u>Traumatic</u>	9	60.0
<i>Motor vehicle accident</i>	2	13.3
<i>Falls</i>	4	26.7
<i>Assaults</i>	2	13.3
<i>Sports - related</i>	1	06.7
<u>Non – traumatic</u>	6	40.0
<i>Viral infection</i>	3	20.0
<i>Cardiovascular accidents</i>	3	20.0
Glasgow Coma Score (GCS)		
Not available	6	40.0
03 – 08 (severe)	5	33.4
09 – 12 (moderate)	2	13.3
13 – 15 (mild)	2	13.3
Time Since Injury (months)		
08 – 12	1	06.7
13 – 16	0	00.0
17 – 20	7	46.65
20 – 24	7	46.65

Protocol

The research protocol was approved by the Queen's University and Affiliated Teaching Hospitals Health Sciences Human Research Ethics Board, and the Bloorview MacMillan Centre Review Committee.

Measurement

Objectives 1 & 2

To address Objectives 1 & 2 of the study, coping was defined as the number and frequency of behaviours engaged in one's effort to deal with or reduce stress (McColl & Skinner, 1995). The coping taxonomy referred to by Pearlin & Schooler (1978) was applied, whereby coping is classified as problem-oriented, perception-oriented or emotion-oriented. The participants were interviewed using the Ways of Coping Scale (WOCS) (adapted from the Ways of Coping Questionnaire (WOCQ), Folkman & Lazarus, 1988; revised by McColl and Skinner, 1995b) (Appendix A). The WOCS asks participants about the relative frequency with which they would apply a variety of coping mechanisms in a stressful situation, which correspond to the strategies of problem-focused, perception-focused and emotion-focused coping (used a great deal, used quite a bit, used somewhat, not at all).

The Ways of Coping Questionnaire measures the coping process, which by definition is variable. Therefore, traditional test, re-test estimates of reliability are inappropriate. Alternatively, reliability is evaluated by the examining the internal consistencies of the coping measures, estimated with Cronbach's coefficient alpha (Folkman & Lazarus, 1988). Internal consistency estimates of coping measures generally

fall at the low end of the traditionally acceptable range. The alpha coefficients for the scales in the Ways of Coping Questionnaire (0.61-0.79) are higher than the alphas reported for most other measures of coping processes (Folkman & Lazarus, 1988). The questionnaire has face validity, as the coping strategies described are those that individuals have reported using to cope with the demands of stressful situations (Folkman & Lazarus, 1988). The questionnaire is consistent with the theoretical predictions that coping is a process, and coping strategies are problem, perception and emotionally based (Folkman & Lazarus, 1988). Many studies have confirmed the reliability and validity of the Ways of Coping Questionnaire (Tennen & Herzberger, 1985; Vitaliano, Russo, Carr, Maiuro & Becker, 1985; Stone, Greenber, Kennedy-Moore & Newman, 1991). Question 21 on the WOCS, “tried to make myself feel better by eating, drinking, smoking, using drugs or medication,” was removed due to its potential reference to the issue of illegal substance abuse, at the request of the Bloorview MacMillan Centre Ethical Review Committee.

Objective 3

Social support was defined according to the three-factor model proposed by House (1981). These factors include instrumental or practical support, emotional support, and informational or guidance support. Perceived availability of social support was measured using an adapted version of the Interpersonal Support Evaluation List (ISEL) (Cohen et al., 1985), the Types of Support questionnaire (TOS) (McColl & Skinner, 1995b) (Appendix B). The Types of Support questionnaire contains 25 questions that correspond to the divisions of instrumental, informational and emotional support outlined by House (1981). Participants are asked to respond based on their

perceptions of the availability of each type of support they have (not applicable, never true, sometimes true, usually true, always true). The last three questions on the Types of Support Questionnaire are overall ratings of satisfaction with each dimension of social support. The ISEL is made up of 40 true-false questions, which ask participants about the perceived availability of others to perform specific support functions, corresponding to four subscales: tangible, appraisal, belonging, self-esteem. Reliability estimates for the ISEL subscales include internal consistency of 0.77-0.90, and test-retest reliability from 0.87 at 2 days to 0.70 at 6 weeks. Concurrent validity was asserted on the basis of significant correlations with the Inventory of Socially Supportive Behaviours (Barrera, 1981) and the Moos Family Environment Scale (Moos, 1974). Construct validation includes significant correlations with number of close friends and relatives, self-esteem, depression, as well as a non-significant correlation with social desirability.

The Family Environment Scale (Short Version) (FES) was used to assess the family unit (Moos, 1974) (Appendix C). The FES is composed of 40 true-false items, which evaluate the social climate of the family. Ten subscales measure the relationships among family members, the directions of personal growth that are emphasized in the family, and the basic organizational structure of the family. Perceptions of the family environment based on cohesion, expressiveness, conflict, independence, achievement orientation, intellectual/cultural orientation, active/recreational orientation, moral/religious affiliation, organization, and control are assessed. The psychometric details and development of the FES are discussed elsewhere (Moos & Moss, 1976). Briefly, the FES was validated from data obtained from more than 1000 individuals and a

representative sample of 285 families. The 10 subscales have moderate to high internal consistencies (ranging from 0.64 to 0.79 using the Kuder-Richardson Formula 20) and acceptable test-retest reliabilities (ranging from 0.68 to 0.86). The average subscale intercorrelation is approximately 0.20, indicating that the subscales measure distinct yet somewhat related aspects of family social environments. Questions 3, “we fight a lot in our family,” and 23, “family members sometimes get so angry they throw things,” were removed from the FES, due to their sensitive nature. If Question 3 or Question 23 were responded to in a positive manner, notification of the proper authorities would have been warranted in connection with suspicion of abuse, which would have violated the terms of confidentiality of the ethical review.

Demographic data including ABI survivor age, gender, education, injury severity and history, as well as parental information regarding age, gender, education, duration of marriage, marital satisfaction, and total household income, were also collected, using a general information sheet (Appendix D). The information was obtained from the participants or, if necessary, from medical records upon consent.

Scheduling and Details of Data Collection

Participants were initially contacted directly by Bloorview MacMillan Centre and the Child Development Centre, using materials provided by the researcher of the study (consent form and information sheet; Appendix D), along with a letter from the centre, outlining the centre’s involvement in the study (Appendix D). To address the issue of fluency in English, potential families were pre-screened by each centre. Families were notified in the letter that they would be contacted further by telephone regarding the

study. If the family did not want to be contacted further, they were instructed in the letter to notify the respective centre, and they were removed from the list of possible participants with no repercussions to themselves or their child. Families were then contacted by telephone, and an interview was scheduled for each participant, at their convenience. At the time of scheduling the interview, any questions or concerns the participants had were answered to the best of the researcher's ability. The parents of each of the participating families were asked not to correspond with one another with respect to the questionnaires and the topics discussed, until both participants had completed the interview process. This request also appeared on the information form. The participants were also asked to complete the interview individually, in an area free from distractions. This request was asked again at the time of the interview. At the time of scheduling the interview, the participants were asked to complete the consent form and the information sheet and mail them back to the principal investigator in the self-addressed stamped envelope provided in the package they received. The responses to the questionnaires (Ways of Coping Scale, Types of Support questionnaire, Family Environment Scale) from each participant were obtained through telephone interviews.

Confidentiality of the participants was ensured at all times throughout the duration of the study. Upon consent, all participants were assigned an identification number, and their name was not used in any instance. Study files were kept in a locked filing cabinet in the Research Room at the School of Rehabilitation Therapy. Only study personnel had access to this room.

Chapter 4: Results

All data were examined for skewness and kurtosis before proceeding with the analyses. Management and analyses of data were performed with the computer statistical programme SPSS Version 8.0 (SPSS INC., 1997). In order for any result to be interpreted as statistically significant, the probability level was equal to or less than 5% ($p \leq 0.05$). Frequency and central tendency data were obtained for all measures utilized in the study (demographic data, Ways of Coping Scale, Types of Support questionnaire, Family Environment Scale).

Objective 1: Prominent Coping Strategies

The prominent type(s) of coping strategies (Objective 1) were determined through analysis of the Ways of Coping Scale. Item level analyses of all 30 items on the questionnaire, as well as an individual subscale analysis of the problem-focused, perception-focused and emotion-focused subscales, were conducted twice. The first analysis examined coping strategies of parents in general, and used the data from all 30 participants. The second analysis investigated the coping strategies of mothers versus fathers, and correspondingly, the participants were split into 2 groups of 15 mothers and fathers, respectively.

Parental Coping Strategies - Item Level Analysis of the Ways of Coping Scale

Item level analysis of the WOCS was performed using a chi-square goodness of fit test to determine the prominent types of coping strategies used by the parents. The

chi-square test analyzed the data for differences in observed frequencies from expected frequencies for each item on the questionnaire. Expected frequencies were equal for all 4 levels of the scale on the questionnaire (not at all (25%), used somewhat (25%), used quite a bit (25%), used a great deal (25%)). The items that were identified as statistically significant were further analyzed, using the frequency data obtained for each item, in order to determine whether the use of the particular coping strategy was higher or lower than expected.

Results of the chi-square analyses yielded 12 out of 30 items as significantly different than would have been expected (refer to Table 3). Four problem-oriented coping strategies, 5 perception-oriented strategies and 3 emotion-oriented strategies were significantly different than would have been expected. To determine whether the use of the strategy was higher or lower than expected, frequency tables were consulted.

Three problem-focused strategies; that is, strategies aimed at directly altering the stressor itself, were used more frequently than would have been expected if all 4 response options had been chosen equally.

- *Item – “knew what had to be done, so doubled my efforts to make things work out right”*

Parents indicated a higher use of this coping strategy than would be expected. Ninety percent of the participants reported “quite a bit” or “a great deal.” In regards to

Table 3: Parental Coping Strategies – Item Level Analysis

<i>Most Frequently used Coping Strategies</i>	<i>Coping Type</i>	<i>X (SD)</i>	<i>median</i>	χ^2	<i>p</i>
-rediscovered what was important in life	perception-focused	2.30(0.99)	3.00	20.40	0.00
-knew what had to be done, so doubled my efforts to make things work out	problem-focused	2.30(0.65)	2.00	7.80	0.02
-reminded myself how much worse things could be	perception-focused	2.13(1.01)	2.00	10.27	0.02
-looked for the silver lining; tried to look on the bright side of things	perception-focused	2.07(0.98)	2.00	8.67	0.03
-changed something so things would turn out right	problem-focused	1.43(0.82)	1.00	11.33	0.01
-came up with a couple of different solutions to the problem	problem-focused	1.33(0.84)	1.00	11.87	0.01

<i>Least Frequently used Coping Strategies</i>	<i>Coping Type</i>	<i>X (SD)</i>	<i>median</i>	χ^2	<i>p</i>
-thought about how a person I admire would handle the situation and used that as a model	problem-focused	0.47(0.78)	0.00	30.53	0.00
-expressed anger	emotion-focused	0.60(0.81)	1.00	10.40	0.01
-got away from it for a while; tried to take a rest or a vacation	emotion-focused	0.67(0.96)	0.00	20.67	0.01
-prepared myself for the worst	perception-focused	1.00(0.95)	1.00	9.20	0.03
-avoided being with people in general	emotion-focused	1.20(0.89)	0.00	10.80	0.00
-told myself things that would make me feel better	perception-focused	1.50(0.97)	1.00	14.00	0.00

their child's injury, the parents in the study were cognizant of what was required and doubled their efforts to make things work.

- *Item – “changed something so that things would turn out right”*

Parents responded with a higher use of the midrange of the scale on the WOCS than would have been expected. With minimal use of extremes of the scale, 80% of parents used this strategy “somewhat” or “quite a bit.” The parents, therefore, used a coping strategy that attempted to change something so that the stressor resulting from the ABI was altered, higher than was expected.

- *Item - “came up with a couple of different solutions to the problem”*

The results of the analysis showed that 77% of parents used this coping strategy more than would be expected for the levels on the WOCS scales of “somewhat” and “quite a bit.” Although parents did not use the extremes on the WOCS scale, the results suggest that quite often parents tried to brainstorm solutions for the challenges that arose following their child's injury, higher than expected.

One problem-focused strategy was used less than expected by the parents in the study.

- *Item – “thought about how a person I admire would handle the situation and used that as a model”*

Parents' use of this strategy was lower than would be expected. Sixty-seven percent of participants responded “not at all” to this strategy. Overall, for the parents in

this study, thinking about a person as a model was not a strategy used to deal with the ABI.

Three perception-focused strategies; that is, strategies aimed at altering the perception of the stressor, were used more frequently than would have been expected if all 4 response options had been chosen equally.

- *Item – “rediscovered what was important in life”*

Sixty percent of parents responded with “a great deal,” when asked the extent to which they use this strategy. The parents of the children with ABI, therefore, used this strategy higher than expected. It is suggested that, for the parents in the study, childhood ABI increased their realizations and reflections of what is important in life.

- *Item – “reminded myself how much worse things could be”*

Parents used this strategy higher than would have been expected. Seventy-seven percent responded with “used quite a bit” or “used a great deal.” The parents consistently reminded themselves that their situation could have been much worse.

- *Item – “looked for the silver lining; tried to look on the bright side of things”*

Frequency data indicated that parent’s used this strategy higher than would be expected, with 77% of parents responding with “quite a bit” and “a great deal.” Thinking positively was a strategy employed by a large percentage of the parents in the study.

Parents in the study reported using two perception-focused strategies less than expected.

- *Item – “prepared myself for the worst”*

The ratings by parents were low on this strategy. Seventy-seven percent of parents responded with “not at all” or “somewhat.” This finding suggests that the parents did not prepare themselves for the worst following their child’s injury.

- *Item – “told myself things that would make me feel better”*

Parents used this strategy less than would have been expected. Frequency data indicated that 19/30 or 63% of parents used the lower half of the scale on the WOCS. This result suggests that the parents did not cope by telling themselves things to make them feel better following childhood ABI.

Three emotion-focused strategies; that is, strategies aimed at altering the emotional response to the stressor, were used less than would have been expected on the WOCS.

- *Item – “got away from it for a while; tried to take a rest or a vacation”*

Parents used this strategy less than expected. The overwhelming majority of participants (93%) reported using this strategy “not at all” or “somewhat.” Following childhood ABI, the parents interviewed in this study did not utilize this strategy often, if at all.

- *Item – “avoided being with people in general”*

Frequency data indicated that parents used this strategy less than expected. Eighty percent of participants’ responses fell on the lower half of the WOCS scale. Parents in this study, therefore, generally did not avoid being with people after their child’s injury occurred.

- *Item – “expressed anger”*

The results indicate that 70% parents did not rely on this strategy. In fact, there was a lower usage than expected for “quite a bit” and “used a great deal” in relation to this strategy. Expressing anger was a strategy not often employed by the participants in this study, when dealing with the outcomes of pediatric brain injury.

Problem-focused, Perception-focused and Emotion-focused Coping Subscale Analysis

To analyze the entire participant sample for differences between coping subscales, a one-way analysis of variance (ANOVA) was conducted. Scores were assigned for each subscale, based on the following scale: “not at all” = 0; “used somewhat” = 1; “used quite a bit” = 2; and “used a great deal” = 3. Summed totals for each subscale were calculated. A significant F value was interpreted through paired comparisons to determine which coping subscale(s) the parents used differently.

The results of the ANOVA yielded a significant F value ($F = 23.02, p = 0.00$). Pairwise comparisons were calculated between all three coping subscales. Parents used problem-focused coping significantly differently than emotion-focused coping (LSD =

5.70, $p = 0.00$), perception-focused coping significantly differently than emotion-focused coping ($LSD = 7.37$, $p = 0.00$), and finally, problem-focused coping significantly differently than perception-focused coping ($LSD = - 1.67$, $p = 0.05$). Upon further examination of the central tendency data, specifically the corresponding mean for each subscale, perception-focused coping was employed the most, followed by problem-focused coping and finally emotion-focused coping. A higher reliance on perception and problem-focused strategies was evident in comparison to the use of emotion-focused strategies by the parents in the study.

Maternal and Paternal Coping Strategies

A Mann Whitney U test was performed on the items of the Ways of Coping Scale to examine the differences (if any) between maternal and paternal use of the particular coping strategies. Any significant differences found were interpreted through analysis of the frequency data obtained for each item for both mothers and fathers. This further analysis allowed for the determination of the extent and direction of the difference between the mothers and fathers in the use of the coping strategy identified as significant. The results of the Mann Whitney U test reflected the coping strategies of the mothers and fathers, in general, and not paired by couple, as in subsequent analyses.

Item level analyses revealed 5 significant differences between mothers' and fathers' use of coping strategies (refer to Table 4). Specifically, 1 problem-focused strategy, 3 perception-focused strategies and 1 emotion-focused strategy were statistically

Table 4: Maternal and Paternal Coping Strategies -- Item Level Analysis

Item	Mothers		Fathers		U	p
	X (SD)	median	X (SD)	median		
<i>problem-focused</i>						
-knew what had to be done, so doubled my efforts to make things work out	2.53 (0.64)	3.00	2.07 (0.59)	2.00	67.50	0.04
<i>perception-focused</i>						
-told myself things that made me feel better	2.00 (1.07)	2.00	1.00 (0.53)	1.00	53.50	0.01
-changed or grew as a person in a good way	2.13 (0.92)	2.00	1.47 (0.74)	1.00	62.50	0.03
-rediscovered what is important in life	2.87 (0.52)	3.00	1.73 (1.03)	2.00	39.00	0.00
<i>emotion-focused</i>						
-avoided being with people in general	1.00 (1.07)	1.00	0.33 (0.72)	0.00	68.50	0.04

different between mothers and fathers. Frequency charts were examined to determine the differences that existed between the mothers' and fathers' use of coping strategies.

Responses on 1 problem-focused strategy were significantly different than expected between mothers and fathers.

- *Item – “knew what had to be done, so doubled my efforts to make things work out”*

Although 90% of mothers and fathers reported using this strategy either “quite a bit” or “a great deal,” the extent to which mothers employed the strategy was higher. Sixty percent of the mothers responded with “used a great deal,” whereas 67% of the fathers reported “used quite a bit.” Both parents recognized what needed to be done and the effort required, however, mothers employed this strategy more often.

Mothers and fathers used 3 perception-focused strategies significantly different than expected.

- *Item – “told myself things that would make me feel better”*

Mothers' responses were spread out across the 4 levels of the WOCS scale, with the majority (47%) indicating “a great deal.” In contrast, fathers used the lower end of scale on the WOCS, with 73% reporting “used somewhat.” Therefore, this particular strategy was used less by fathers and more by mothers. Following childhood ABI, the mothers altered their perception of the situation so that they felt better more so than the fathers.

- *Item – “changed or grew as a person in a good way”*

Mothers reported using this strategy either “quite a bit” (40%) or “a great deal” (40%), whereas fathers responded with “somewhat” (47%) or “quite a bit” (40%). The fathers reported that they changed or grew as a person in a good way to a lesser extent than the mothers, when dealing with the outcomes of pediatric acquired brain injury.

- *Item – “rediscovered what was important in life”*

The fathers’ responses for this strategy were spread out over the levels of the scale on the WOCS, with only 27% reporting “used a great deal.” Ninety-three percent of mothers, on the other hand, reported employing this strategy “a great deal.” Although the fathers re-evaluated the important things in life, the extent to which the mothers used this coping strategy was much greater, suggesting that the mothers needed to put a greater emphasis on what they view as important, after ABI.

The mothers in the study used 1 emotion-focused strategy significantly different than did the fathers.

- *Item – “avoided being with people in general”*

Although the majority of parents (80%) responded using the lower end of the WOCS scale, 80% of fathers reported “not at all,” whereas only 40% of mothers responded with “not at all.” This result indicated that the mothers avoided being with people more so than the fathers, following the onset of their child’s injury.

Maternal and Paternal Coping – Subscale Analysis

The data from the mothers and fathers were then analyzed for differences in overall scores on the 3 coping subscales measured by the WOCS. An independent t-test was used to determine if differences existed between maternal and paternal use of problem-focused, perception-focused and emotion-focused coping. Central tendency data were consulted to interpret significant differences that arose.

The only significant difference that arose from the data was on the perception-focused coping subscale ($t = 2.484$, $p = 0.019$). Based on the central tendency data, the mothers used perception-focused coping to a greater extent than did the fathers. That is, the mothers responded consistently more often with “used quite a bit” and “used a great deal” than did the fathers (mean mothers $x = 19.67$, $sd = 4.37$; fathers $x = 15.60$, $sd = 4.60$). The mothers changed their perceptions of the stressors that arose following the acquired brain injury more so than did the fathers, in order to cope with the outcomes of the injury (refer to Table 5).

Objective 2: Relationship Between Types of Coping Strategies Within Families

The relationships between maternal and paternal coping strategies within couples (Objective 2) were determined through item and subscale analyses of data from the Ways of Coping Scale. For all analyses pertaining to Objective 2 mothers and fathers were matched by child. Therefore, the outcome of the analyses reflected the relationships of coping strategies within couples.

Table 5: Coping Repertoire

Coping Subscale	Mothers		Fathers	
	X(SD)	Median	X(SD)	Median
Problem	16.80(4.52)	17.00	15.13(4.52)	14.00
Perception	19.67(4.37)	21.00	15.60(4.60)	17.00
Emotion	10.40(3.89)	11.00	10.13(3.78)	11.00

Individual Items used “Quite a Bit” or “a Great Deal” by Each Parent

Item (Ways of Coping Scale)	Mothers (/15)	Fathers (/15)
Problem-focused		
doubled my efforts	14	13
found out more	11	9
stood my ground	11	6
made a plan of action	10	6
talked to someone	9	8
changed something	9	6
came up with solutions	7	5
drew on past experience	5	8
went over it in my mind	4	5
thought about a role model	3	4
Perception-focused		
rediscovered importance in life	15	9
looked for the silver lining	13	10
changed or grew as a person	12	7
could always be worse	11	11
came out better than went in	9	7
told myself things	9	2
maintained my pride	8	7
was inspired to be creative	7	7
accepted it	5	5
asked a friend for advice	4	2
prepared for the worst	2	0
Emotion-focused		
kept others from knowing	10	10
let my feelings out somehow	10	8
tried to change someone's mind	9	9
turned to work or other activity	5	4
things will be different next time	5	3
kept my feelings to myself	4	6
avoided being with others	3	8
expressed anger	3	6
got away for a while	0	2

Coping within Couples – Item Level Analysis

Item level analysis of the 15 matched couples data from the WOCS was performed using a Wilcoxin Signed-Ranks test. Items that were identified as significant were analyzed across all 15 couples to determine the nature of the differences in use of the particular coping strategy. Paired responses between the mothers and fathers were consulted to interpret the significance.

Four of 30 items were found to be significantly different between mothers and fathers within couples (refer to Table 5). Three items were perception-focused strategies, and the fourth was an emotion-focused strategy.

Mothers and fathers within couples employed 3 perception-focused strategies significantly different than expected.

- ***Item – “told myself things that made me feel better”***

Analyses of all 15 couples showed that in 12 instances, the fathers of the couples used the coping strategy less than did the mothers. Only 3 couples rated the use of this strategy exactly the same. Therefore, within couples, the mother told herself more often things that made her feel better, in comparison to the fathers.

- ***Item – “changed or grew as a person in a good way”***

Ten out of 15 couples’ responses showed the mothers employed this strategy to a greater extent than did the fathers. Two couples indicated the same use of this coping

Table 6: Coping within Couples – Item Level Analysis

Item	Mothers		Fathers		T	p
	X (SD)	median	X (SD)	median		
<i>perception-focused</i>						
-told myself things that made me feel better	2.00 (1.07)	2.00	1.00 (0.53)	1.00	-2.38	0.01
-changed or grew as a person in a good way	2.13 (0.92)	2.00	1.47 (0.74)	1.00	-2.14	0.03
-rediscovered what is important in life	2.87 (0.52)	3.00	1.73 (1.03)	2.00	-2.71	0.01
<i>emotion-focused</i>						
-avoided being with people in general	1.00 (1.07)	1.00	0.33 (0.72)	0.00	-2.07	0.04

strategy. In 3 instances, the fathers utilized this strategy more often than the corresponding mother did. On the whole, within couples, the mothers changed or grew as a person more so than the fathers following childhood ABI.

- *Item – “rediscovered what was important in life”*

With the exception of one mother, all mothers of the couples rated this coping strategy with “used a great deal.” In contrast, the fathers reported using this strategy to a lesser extent. Four couples indicated the same use of the coping strategy and in 1 couple, the father used the strategy more often than did the mother. Similar to the comparison of mothers and fathers in general, perceiving what is important in life was a coping strategy employed more frequently for the mother within the couple, than the father.

In terms of emotion-focused strategies, mothers and fathers within couples differed significantly in their use of 1 strategy.

- *Item – “avoided being with people in general”*

Twelve of the 15 fathers reported using this strategy “not at all.” Two instances where the mother within the couple reported a higher use of avoiding people than the father were documented. In 13 instances, the mother employed this strategy more often than did the father. Therefore, within couples, the mothers in this study avoided people more as a coping strategy when compared to the father following pediatric ABI.

Coping within Couples - Subscale Analysis

Two different analyses were performed to investigate the use of the coping subscales within couples. First, the 3 subscales were examined for differences in use of problem, perception and emotion-focused coping within couples. Second, the relationship between the coping subscales within couples was determined (refer to Figure 2).

(a) Differences between Coping Subscales

A paired t-test was performed to investigate the differences (if any) within couples use of problem-focused, perception-focused and emotion-focused coping. Significant findings were explained through the examination of the paired scores for each couple on the identified subscales.

The results of the paired t-test indicated the presence of only one significant difference between the use of coping subscales within couples. Mothers and Fathers within couples were significantly different on the perception-focused subscale. Examination of the paired scores for each couple on the perception-focused subscale showed that mothers had a higher mean than fathers (mothers $x = 19.67$; fathers $x = 15.60$). Within couples, mothers used perception-oriented coping strategies more than fathers. In order to deal with the pediatric ABI, the mother within the couple altered her thoughts about the outcomes of the ABI to a greater extent than did the father.

(b) Relationship between Coping Subscales

To analyze the relationship (supplementary or complementary) between maternal and paternal coping strategies, Pearson correlations were used. Two-tailed Pearson correlations were calculated between each of the two groups (mothers and fathers) for all combinations of the coping subscales (refer to Figure 2). The strength and direction of the relationships were determined and interpreted based on their correlation coefficient and its corresponding significance level. The results appear in Figure 3.

Of all 9 possible combinations, only 2 were found to be statistically significant. The correlation between maternal and paternal problem-focused coping was significant, yielding $r = -0.792$, $p = 0.001$, suggestive of a strong negative/reciprocal relationship. That is, when mothers employed problem-oriented coping, fathers did not, or, when fathers used problem-focused coping, mothers did not. Maternal perception-focused coping was also negatively correlated with paternal problem-focused coping, $r = -0.537$, $p = 0.039$, indicating that when the female of the couples used perception-focused coping, the males did not use problem-focused coping, or, when the male employed problem-focused coping, the corresponding female did not use perception-oriented coping strategies.

Eight of the 9 correlations resulted in negative correlates between maternal and paternal coping within couples, ranging from $r = -0.129$ to $r = -0.792$, although only the two mentioned above were significant. Only one combination yielded a positive

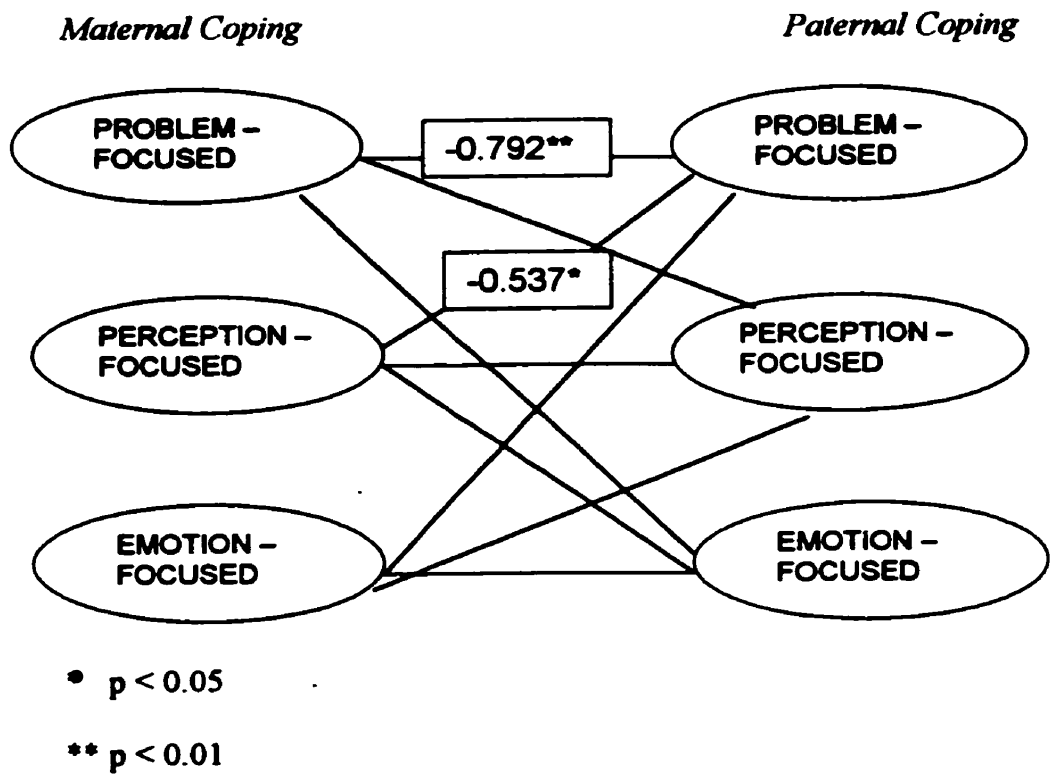


Figure 3: Relationships between Maternal and Paternal Coping

correlation of $r = 0.91$, $p = 0.746$, between maternal and paternal perception-oriented coping.

It appears that there may be some complementarity in the relationship between maternal and paternal coping (refer to Figure 2). When one parent utilized a particular type of strategy, the other did not rely on the same strategy to the same extent. However, the usual interpretation of complementarity was not shown in this data. A true complementary relationship involves one partner contributing one kind of coping, and the other complementing his or her efforts by supplying the other two (McCull & Skinner, 1995b). Thus, the relationship between maternal and paternal coping in this study is suggested as complementary, only to a certain extent, as a balance of strategies was not found.

Objective 3: Social Support, Family Environment and Coping

Objective 3 addressed the extent to which social support and the family environment affected parental coping, as assessed by the Types of Support questionnaire (TOS) and the Family Environment Scale (FES).

Social Support

Social support was evaluated in both parents. The perceived overall availability of all 3 types of support (instrumental, informational and emotional) for parents was high, suggestive of well-developed social networks. Based on the theory that social support is a coping resource (Thoits, 1986), the findings of the study suggest that the parents had

well-defined support networks which were readily accessible during the coping process. Tangible assistance or instrumental support, cognitive guidance or informational support and emotional support were all available, as over 50% of the participants reported a score of higher than 80% availability on each of the three divisions of support (refer to Table 6).

The results obtained from the Types of Support questionnaire (McColl & Skinner, 1991) for the dimensions of instrumental, informational and emotional support were correlated with the subscales of problem-focused, perception-focused and emotion-focused coping to determine the relationships between social support and coping in parents of pediatric ABI survivors. In order to determine the strength and direction of the relationships, two-tailed Pearson correlations were calculated. The strength and direction of the relationships were interpreted from the resulting correlation coefficients and their respective significance.

All possible combinations of correlations were calculated. The results are shown in Figure 4. Only one correlation was significant. The correlation between instrumental support and emotional coping resulted in a significant relationship in the positive direction ($r = 0.389$, $p = 0.034$). This suggests that when the parents had support that addressed the source of the stressor in the form of practical help, they were more likely to engage in emotion-focused coping. Alternatively, it could be interpreted that the parents who employed emotion-focused coping attracted a large amount of instrumental or practical support.

Table 7: Social Support – Descriptive Statistics

(a) Parents

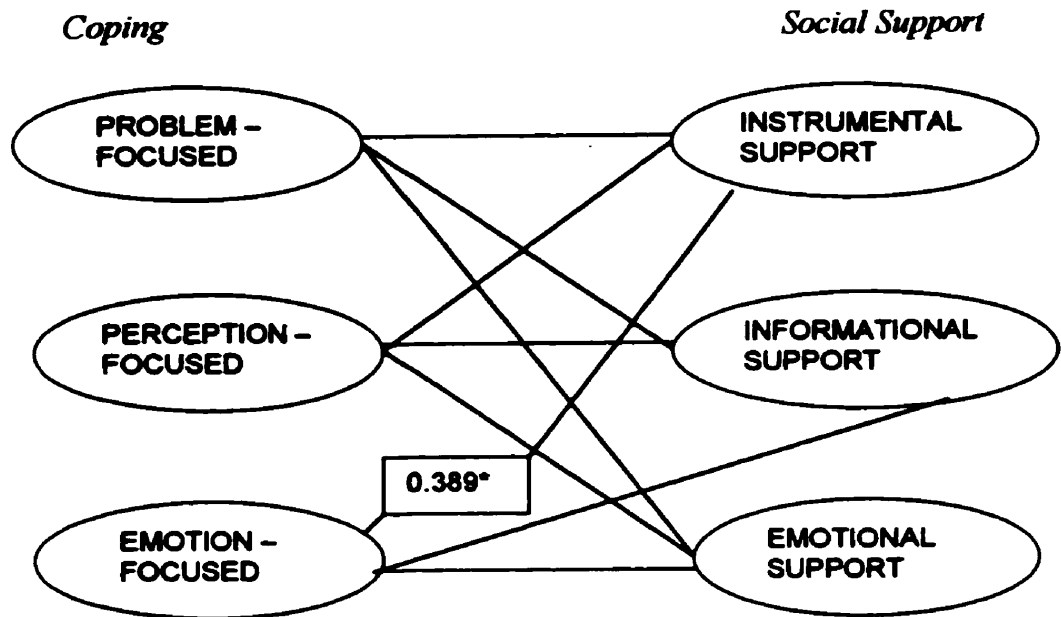
Availability of Support (Item Totals)	X (SD)	median
<i>Instrumental Support (/21)</i>	17.10(3.68)	17.50
<i>Informational Support (/18)</i>	14.17(3.54)	14.00
<i>Emotional Support (/27)</i>	22.07(3.73)	23.00

Satisfaction with Support (Overall Rating /10)	X(SD)	median
<i>Instrumental Support</i>	7.23(1.38)	7.00
<i>Informational Support</i>	7.33(1.12)	7.50
<i>Emotional Support</i>	7.53(1.81)	8.00

(b) Mothers versus Fathers

Availability of Support (Item Totals)	Mothers		Fathers	
	X(SD)	Median	X(SD)	Median
<i>Instrumental Support (/21)</i>	16.40(4.48)	17.00	17.80(2.62)	18.00
<i>Informational Support (/18)</i>	14.33(4.10)	14.00	14.00(3.02)	13.00
<i>Emotional Support (/27)</i>	22.40(3.64)	23.00	21.73(3.92)	22.00

Satisfaction with Support (Overall Rating /10)	Mothers		Fathers	
	X(SD)	Median	X(SD)	Median
<i>Instrumental Support</i>	7.20(1.08)	7.00	7.47(1.19)	8.00
<i>Informational Support</i>	7.07(1.53)	7.00	7.40(1.24)	7.00
<i>Emotional Support</i>	7.60(1.80)	8.00	7.47(1.88)	7.00



* $p < 0.05$

Figure 4: Relationship between Coping and Social Support

Family Environment

Parental perceptions of their family environment were assessed by the Family Environment Scale. The results of the FES were analyzed for differences in responses on the 10 areas of family functioning examined. No significant differences were found between mothers and fathers within couples for any of the 10 family functioning subscales. Mothers and fathers, therefore, responded similarly when asked for their perceptions of all areas of family functioning assessed by the Family Environment Scale (refer to Table 8).

To investigate the relationship between parental coping and the family environment, the 10 subscales measured by the FES (cohesion, expressiveness, conflict, independence, achievement orientation, intellectual/cultural orientation, active/recreational orientation, moral/religious orientation, organization and control) were correlated with each of the 3 subscales of coping obtained on the Ways of Coping Scale (problem-focused, perception-focused and emotion-focused coping) (refer to Table 7). Two-tailed Pearson correlations were obtained in order to determine the strength and direction of any relationships. Significant correlations were interpreted based on the strength and direction of the identified relationship(s).

The correlation between perception-focused coping and family cohesion was statistically significant ($r = 0.365$, $p = 0.048$). This suggests that when the parents used perception-focused coping, they reported a higher level of family cohesion. Parents

Table 8: Family Functioning – Descriptive Statistics

Overall Family Functioning

Mean (X) (/38)	25.1
Standard Deviation (SD)	3.96
Median	24
Range	18 - 34

Areas of Family Functioning

Area	Mean (X)	Median
Cohesion	3.63	4
Intellectual/Cultural	2.90	3
Organizational	2.70	3
Expressiveness	2.63	3
Active/Recreational	2.50	3
Achievement	2.37	3
Independence	2.53	2
Control	2.37	2
Religious/Moral	2.33	2
Conflict	1.13	1

**Table 9: Relationships between Family Environment and Coping
(Pearson Correlation Coefficients (r values))**

FES Subscale	Problem-focused Coping	Perception-focused Coping	Emotion-focused Coping
Cohesion	0.219	0.365*	0.228
Expression	-0.250	-0.100	-0.218
Conflict	-0.126	-0.122	-0.123
Independence	-0.004	-0.135	-0.023
Achievement	-0.040	-0.079	-0.102
Intellectual	0.206	0.015	-0.111
Activity	0.103	-0.068	0.259
Moral	0.199	0.244	0.068
Organization	0.109	0.130	0.121
Control	0.121	0.207	-0.149

* $p \leq 0.05$

altered their perceptions of the ABI, and by doing so perceived their family environment as a more cohesive unit. On the other hand, it may be interpreted that families who reported a high level of family cohesion used perception-focused coping. Parents who perceived their family unit as cohesive, used perception-focused coping in dealing with the outcomes of their child's ABI. All other correlations were non-significant.

Chapter 5: Discussion

This study examined parental coping following onset of childhood brain injury. The investigation of coping strategies, as well as factors that may affect parental coping was conducted. Specific information was sought in order to determine the prominent coping strategies used by parents following pediatric acquired brain injury, the relationship between maternal and paternal coping, and the effect of social support and family environment on parental coping.

The parents of 15 children with acquired brain injury completed the Ways of Coping Scale (Lazarus & Folkman, 1988; revised McColl & Skinner, 1995b), the Types of Support Questionnaire (revised from the Interpersonal Support Evaluation List Cohen et al., 1985 by McColl & Skinner, 1995b), the Family Environment Scale (Moos, 1974) and provided relevant demographic data pertaining to the study.

The results of the study indicate 4 main findings. First, the most commonly used types of coping strategies used by the parents were perception-focused strategies. Coping strategies directed at altering the perception of the brain injury were most commonly reported. Second, the mothers had a larger coping repertoire than the fathers. Mothers reported using more strategies often or always when compared to fathers. Third, a relationship between maternal and paternal coping was found. The results suggest that the relationship is complementary in nature. That is, when one parent employed a coping

strategy a great deal, the other parent did not use the same strategy very much. Last, relationships between coping and social support and coping and the family environment were found. A relationship exists between instrumental or practical support and emotion-focused coping, as well as between family cohesion and perception-focused coping.

Prominent Coping Strategies

The prominent types of coping strategies used by the parents following pediatric ABI were perception-focused strategies. These perception-focused coping strategies consisted of cognitive attempts by the parents to control the meaning and interpretation of the outcomes of their child's acquired brain injury. This finding was consistent across the analyses of the parents in general, as well as the subsequent comparative analyses of mothers and fathers and couples, respectively.

A number of coping strategies of parents with a child with cancer have been identified. Both problem and emotion-focused strategies have been identified, however the majority of studies reported a higher usage of problem-oriented strategies, such as communication, information and support seeking, and problem-solving (Barbarin & Chesler, 1986; Koocher & O'Malley, 1981; Kupst & Schulman, 1988; Spinetta et al., 1988). Barbarin & Chesler (1986) interviewed 74 parents of surviving children with cancer. Parents reported that they coped reasonably well by using information seeking, problem-solving, help-seeking, maintaining emotional balance, relying on religion, being optimistic, denying, and accepting, with respect to their child's condition. More highly

educated parents tended to use problem solving, optimism, and information seeking significantly more and denial significantly less than other parents. Gender and incomes were unrelated to coping. In an earlier study, Barbarin and colleagues (1985) found that open communication, one day at a time, reliance on religion, seeking support and seeking information, were the most commonly used coping strategies by parents of pediatric cancer survivors.

Parents used a combination of both problem- and emotion-focused coping, in a study conducted by LaMontagne & Pawlak (1990) which investigated parental coping of childhood cancer patients. Seeking social support and positive reappraisal were the two most often used strategies by all parents.

In comparison, research on the coping strategies of parents caring for a disabled child emphasizing the process model of stress and coping (Lazarus & Folkman, 1984), and the importance of focusing on specific responses to specific stressors, has only recently been used in this area of research (Beresford, 1994). Numerous studies have documented parents' views of which coping strategies are most helpful, however, only a handful have utilized the model proposed by Lazarus & Folkman (1984) (Bregman, 1980; Brown & Hepple, 1989; Brisol, 1984).

Bregman (1980) identified various coping strategies used by parents, the majority of which were problem focused, including take each day as it comes, maintain a lifestyle

as normal as possible, keep well-informed, seek out the best options for their child's health, trouble-shoot and monitor the standard of services received by your child.

Parents of multiply disabled children reported using strategies such as, talking to one's spouse, reminding oneself how much worse it could be, restructuring the situation using humour, focusing on the positive aspects, one day at a time, and using formal support as the most effective coping strategies for dealing with situations regarding their child's disabilities (Brown & Hepple, 1989).

Brisol (1984) identified coping strategies employed by parents of autistic children. Many of the strategies were problem focused and perception focused including: learning how to help their children improve, doing things with their children, believing in the intervention program their child was involved in, believing in God, and believing their child would get better.

In most of the studies described above, the coping dimensions identified were consistent with the classification of coping defined by Lazarus & Folkman (1984), which divides coping into problem-focused strategies and emotion-focused strategies. The current study utilized the coping subscales defined by Pearlin & Schooler (1978), which includes a third division of coping, perception-focused strategies. A limitation of the above studies was the failure to incorporate perception-focused strategies as a distinct category. Information may have been lost. The present study highlights the importance of measuring perception-focused strategies as a dimension of coping, as the most

commonly reported strategies employed by the parents, as well as the subdivisions of mothers and fathers and couples, were perception-focused.

The inconsistency in the prominent coping strategies of parents of pediatric cancer patients and parents of children with ABI may be due to the inherent differences of the course of each diagnosis. Parents of pediatric cancer patients live with the threat of relapse or death for years (Koocher & O'Malley, 1981). Apart from this continuous uncertainty about the eventual outcome of the diagnosis, repeated hospitalizations, invasive treatments with distressing side effects, and constant alterations in family routine all contribute to the chronicity of the disease. In contrast, parents of children with ABI are the primary caregivers of the child following discharge. Repeated hospitalizations are rare, and once the child is medically stable, the parents are largely responsible for his/her integration back into the community, as well as dealing with all of the resultant outcomes of their child's injury, including such consequences as behavioural difficulties and cognitive impairments. The types of coping strategies utilized by parents, may therefore be affected by the unique context of each diagnosis.

In comparison, a consistent finding across studies which have examined coping strategies employed by parents of children with a disability, was that active coping strategies are important to the well-being of parents caring for a disabled child. Both qualitative and quantitative studies report the usefulness of active coping (e.g. Bregman, 1980; Glidden et al., 1993; Miller et al., 1992; Minnes & Nachshen, 1998; Shapiro et al., 1998; Sloper et al., 1991; Thompson et al., 1992). This includes planning, direct

problem-solving and information seeking. As well, certain cognitive coping strategies also appear to be adaptive. Positive restructuring and self-praise appeared to be useful or adaptive coping strategies in a number of studies (e.g. Affleck & Tennen, 1993; Bregman, 1980; Brown & Hepple, 1989; Minnes & Nachshen, 1998; Thompson et al., 1992). Cognitive restructuring is the process by which parents change their appraisal of their situation or an aspect of their child's disability. Thus, the situation can be viewed in such a way that it no longer causes distress (Beresford, 1994).

The use of perception-focused strategies in the present study supports the findings of Affleck & Tennen (1993), Bregman (1980), Brown & Hepple (1989), Minnes & Nachshen (1998) and Thompson and colleagues (1992). Similar use of perception-focused strategies was found in both the aforementioned studies, as well as the current one. Parents dealing with the outcomes of childhood disability may, therefore, encounter similar stressors to the parents of the pediatric ABI survivors in this study. In both cases, the parents are largely responsible for the care of their child, once the child is medically stable.

Pediatric ABI results in continual challenges for parents. Although many situations that arise may be dealt with by active problem-focused strategies, the presence of the ABI required a constant re-framing of the situation by parents in this study. In order to deal effectively with the day to day effects of the ABI on the child and the family unit, parents in this study altered their perceptions of the ABI. It is suggested that some of

the stresses the parents have to cope with cannot be resolved, instead they have to be lived with.

The findings of the present investigation support a study of family adaptation following childhood ABI, where meaningfulness was predictive of family adaptation suggesting that family adaptation to acquired brain injury may be largely influenced by a family's view of the ABI situation (Koseiulek, 1997). That is, the difference between events that lead to dysfunction and those that lead to successful coping depends upon the family's interpretation of the event. The process of positive appraisal involves the family redefinition of stressful events to make them more meaningful. In the face of brain injury, the family is called upon to appraise its past and future in an attempt to give meaning to the injury and the resulting changes in the family system needed to facilitate adaptation. The family that views a brain injury as a manageable family challenge will most likely adapt more successfully than a family that views the brain injury as catastrophic (Koseiulek, 1997).

The finding of perception-focused coping strategies also supports a study by Minnes and colleagues (2000). Coping and stress of caregivers of individuals with traumatic brain injury was examined. The results indicated that coping strategies whose functions were to reframe the stressor and acquire social support were important contributors to the reduction of stress. The function of coping strategies that reframe the stressor in the study conducted by Minnes and partners was synonymous to the function of perception-focused strategies in the present study.

Coping Repertoire

The results of the study indicate that the mothers had a larger coping repertoire when compared to the fathers. Mothers utilized significantly more coping strategies than fathers both in general, and within couples, as evidenced by the item level analyses, as well as the subscale analyses. Item level analyses indicated that the mothers reported using coping strategies “quite a bit” or “a great deal” significantly more often than fathers (refer to Tables 4 & 5). As well, overall subscale scores were consistently higher for mothers than for fathers on the problem and emotion-focused coping subscales, and significantly higher on the perception-focused subscale.

The finding of a larger coping repertoire for the mothers in contrast to the fathers is inconsistent with the observations of Hoekstra-Weebers and colleagues (1998a, 1998b), where no gender differences in coping repertoires were found between parents of pediatric cancer patients one-year post-diagnosis. Two other studies of parents of pediatric cancer patients also reported no gender differences in coping (Barbarin & Chesler, 1986; Hoeskstra-Weebers et al., 1992). A larger coping repertoire for mothers also contradicts the findings of Chesler & Barbarin (1987), who observed that gender differences arose dependent upon the subscale of coping employed. Fathers used more emotion-focused strategies such as denial than did mothers and mothers employed more problem-focused strategies, including information seeking than did fathers. Larson and colleagues (1994) found that mothers engaged in active-problem solving strategies more

than fathers, suggesting that the mothers had a larger problem-focused coping repertoire than did the fathers.

The differences between the finding of a larger repertoire for mothers of the current study in comparison with pediatric cancer literature may have occurred as a result of a greater compliance rate for women when completing questionnaires (Verbrugge, 1985). It has been suggested that women may report more information than men, as it is more socially acceptable for them. However, the opposite may also be true with men being less inclined to report or deny their distress. The effect of gender may not be transferable to the context of pediatric ABI. Instead, it is suggested that the presence of a larger coping repertoire for the mothers in the current study promotes effective coping, leading to positive adaptation following childhood ABI.

With respect to pediatric disability literature, studies suggest that an extensive coping repertoire may be beneficial, and the coping repertoire for mothers is often larger than that of the father (Bregman, 1980; Frey et al., 1989; Sloper et al., 1991; Sloper & Turner, 1993). Bregman (1980) noted that an important aspect of parental coping was to maintain and develop vast coping resources. Parents developed and capitalized their personal strengths, in order to deal effectively with their child's disability. In other studies, the relationship between the amount of use of coping strategies and adjustment was investigated. The results indicate that the coping repertoire appears to be less pronounced for fathers than mothers when coping with a child with a disability (Frey et al., 1989; Sloper et al., 1991; Sloper & Turner, 1993).

Once again, the findings of the present study were in contrast to those of pediatric cancer literature, but consistent with the literature regarding childhood disability. The consistency that mothers have a larger coping repertoire than fathers, both in the current study, and in pediatric disability literature furthers the suggestion that similarity may be present between these two diagnoses, resulting in similar coping efforts.

Pearlin & Schooler (1978) (p. 14) suggest that “the sheer richness and variety of responses that one can bring to bear in coping with life-strains may be more important than the nature and content of any single coping element.” Possessing fewer coping responses maximizes the likelihood of the presence of stress associated with the situation, and being able to call on more of these strategies minimizes the chances. By having a large coping repertoire, the mothers in this study may have more effectively dealt with the various stressors that arose from their child’s ABI.

Relationship Between Maternal and Paternal Coping

A relationship between maternal and paternal coping was found. The results suggest that the nature of the relationship was complementary. When one parent employed a particular coping strategy, the other parent did not use the same strategy very much, if at all. Specifically, two significant reciprocal relationships were obtained between maternal and paternal coping. First, a reciprocal relationship between maternal and paternal problem-focused coping was evident. Second, a reciprocal relationship was found between maternal perception-focused coping and paternal problem-focused coping.

Past studies have focused on examining coping in terms of its presence or absence and usage by caregivers of persons with ABI. However, these studies have not investigated both parents, nor has the relationship between coping been determined in the ABI literature. Few studies have examined the relationship in coping among parents of pediatric cancer patients without relating it to another variable, most commonly marital satisfaction (Barbarin et al., 1985; Dahlquist et al., 1993; Hoekstra-Weebers et al., 1998a; Koocher & O'Malley, 1981; Kupst & Schulman, 1988) or psychological distress (Hoekstra-Weebers et al., 1998a, 1998b). The results of this study are contradictory to findings investigating the relationship(s) of coping in parents of pediatric cancer patients. Hoekstra-Weebers and colleagues (1998b), investigated the relationship between coping strategies of mothers and fathers at diagnosis and 6 and 12 months post-diagnosis of pediatric cancer. The coping strategies of active-problem focusing, palliative reaction pattern, avoidance behaviour, social-support seeking, passive reaction patterns, expression of emotion and comforting cognitions were measured. Only positive relationships were found at all three time periods between maternal and paternal coping. The correlations did not reach a high level of significance, however the tendency towards similarity than dissimilarity in coping within couples was reported.

Complementarity in problem-focused coping found in the present study, supports one of the findings in a study conducted by Barbarin and partners (1985). Barbarin and colleagues (1985) explored the congruence of parents' coping strategies in dealing with their child's cancer. Partners whose coping styles were complementary with respect to the use of problem-focused coping reported better marital functioning. In contrast,

symmetry in the use of optimism as a coping style was associated with better marital functioning. The results suggest the nature of the relationship is complex, and the adaptive form of congruence differs between coping dimensions and the strategies within them.

The finding of complementarity in the present study, however, is also in contrast with the study of Blotcky and partners (1985), who found that mothers' and fathers' coping behaviour following pediatric cancer onset was unrelated. Blotcky and partners (1985) used the coping health inventory for parents (McCubbin et al., 1983) designed to be used by parents of medically ill children and measures: family integration, personal stability and understanding the medical situation of the child.

These differences in conceptualization make comparison of the results of the aforementioned studies with the present one difficult. The use of different questionnaires, different populations and times following diagnosis, may all factor into the coping patterns parents utilize following onset of childhood cancer versus pediatric ABI. As well, the studies cited above included parents who may have been separated or divorced at the time(s) of data collection, whereas the present study focused only on intact, two parent (not necessarily biological) families.

The significant reciprocal relationship between maternal and paternal problem-focused coping following childhood ABI may be due to numerous factors. If one parent is engaging in active problem-focused coping, the other parent may take the opportunity

to use less problem-focused coping in order to gain respite from the situation. On the other hand if both parents use problem-focused coping strategies, it may lead to confusion and frustration as too many attempts to deal with the situation in a similar “hands on” manner are being made. Alternatively, problem-focused coping strategies may be delegated to one parent, and therefore the other parent does not interfere by engaging in problem-focused coping as well. Last, psychological literature suggests that active coping of one individual, such as problem-focused coping, may undermine the active coping of another. Thus, one individual is over-functioning and the other is under-functioning with respect to their active coping (Hendrix, 1990).

The second reciprocal relationship identified between maternal perception-focused coping and paternal problem-focused coping may be explained through behaviour exhibited by the parents coined, “wait and see.” That is, when the mother employs perception-focused coping strategies, the father does not utilize problem-focused strategies, but instead waits to see if the mothers efforts alter the stress of the situation arising from the ABI. On a similar note, if the father engages in problem-oriented coping, the mother refrains from using perception-focused strategies to deal with the situation, and waits to see if the fathers’ attempts to alter the stress associated with the ABI.

Coping in Relation to Social Support and Family Environment

Upon analysis, relationships between social support and coping, as well as between the family environment and coping were found. In particular, significant positive relationships resulted between instrumental support and emotion-focused coping, and family cohesion and perception-focused coping.

Social Support

The perceived overall availability of all 3 types of support for parents in the study was high. Instrumental, informational, and emotional support networks were perceived as readily available, and accessible (refer to Table 6). Few studies have investigated social support and coping in caregivers of pediatric ABI survivors. Most studies have employed measures to determine the presence or absence of support, as well as the amount of support available to the caregiver. In a study by Saunder and colleagues (1997), caregiver satisfaction was significantly related to social support. Studies of family adjustment have shown that strong support systems were strong predictors of positive adjustment over time (Douglas & Spellacy, 1996; Minnes et al., 2000; Rivara et al., 1996; Waaland & Kreutzer, 1988). Douglas & Spellacy (1996) found that, in particular, instrumental or practical support appeared to be essential to family functioning.

Both pediatric cancer and childhood disability literature underscore the importance of the availability of social support in successful adaptation to these conditions (e.g. Bristol, 1979; Heninen & Knygas, 1998; Minnes, 1988; Minnes et al., 1989; Minnes et al., 1999; Quitner, Gluekajf & Jackson, 1990; Quine & Pahl, 1985; Sherman & Cocozza, 1984, Speechly & Noh, 1992; Trivette & Cross, 1986; Venters, 1981). Emotional and instrumental support were connected to adaptation of parents with a chronically ill child (Heninen & Knygas, 1998). The presence and use of emotional and practical support were necessary for the parents to adapt on a day to day basis with their child. Social isolation, or lack of social support, can be one of the most stressful factors associated with caring for a disabled child (Bristol, 1979; Quine & Pahl, 1985). Parents who do not receive support, or utilize support networks when dealing with a disabled child report higher stress levels than parents who have a well-defined support network. Parents of cancer survivors experiencing low levels of social support were more depressed and anxious than parents of children without cancer (Speechly & Noh, 1992). A support system was critical to lowering depression levels, and enabling better adaptation.

According to theory, the social environment may influence both the actual choice of a specific coping strategy and the skill in which this strategy is performed (Holoohan & Moos, 1987, 1990, 1991; Thoits, 1986). Thoits (1986), stated that when coping, the social environment may help the individual to cope, and that the availability and use of social support resources generally contributes to more adaptive coping strategies. The findings of the current study suggest that the presence of an extensive support environment

reported by the participants, may have influenced their ability to cope with pediatric acquired brain injury, and may have aided in their use of adaptive coping strategies.

The relationship between social support and coping was also investigated. A positive relationship was found between instrumental support and emotion-focused coping (refer to Figure 4). Therefore, when parents had instrumental or practical support, they engaged in the use of emotion-focused coping strategies. Alternatively, when parents employed coping strategies aimed at altering their emotional response to the situation arising from the ABI, the perceived availability of supports directed at altering the situation was high.

Emotion-focused strategies are thought to be associated with negative adaptation in controllable situations, whereas problem-focused strategies are thought to be adaptive in situations that may be controlled (Conway & Terry, 1992; Folkman et al., 1979; Forsythe & Compas, 1987; Glidden et al., 1993; Quine & Paul, 1991; Shapiro et al., 1998; Terry, 1994; Thompson et al, 1992; Vitaliano et al., 1990). A study by Frey and partners (1989) examined the relationship between coping strategies and psychological distress in parents of disabled children. Mothers and fathers who used problem-focused strategies experienced less stress and psychological distress. In contrast, 3 emotion-focused coping strategies were associated with poorer outcomes: avoidance coping, wishful thinking, and self-blame. Miller, Gordon, Daniele & Diller (1992) found that emotion-focused coping was related to increased psychological distress in mothers of

disabled children, whereas problem-focused coping was associated with decreased distress.

Although emotion-focused coping is often associated with negative outcome and adaptation, the degree to which families allow emotional expression is another important family environment factor (Beresford, 1994). Studies have consistently shown that prohibition of emotional expression has adverse effects on a family's adaptation to chronic illness (e.g. Koch, 1983,1985). Thompson and partners (1992) and Miller and colleagues (1992) both found emotion-focused strategies positively associated with poor adjustment. In contrast the findings from qualitative studies suggest that parents find certain emotion-focused strategies very helpful (e.g. Bergman, 1980; Bristol, 1984; Brown & Hepple, 1989). Certain situations were less stressful when emotion-focused strategies were employed.

In relation to the above studies, the finding of the positive relationship between emotion-focused coping and instrumental social support suggests that in the presence of a strong support system, parents may be able to use emotion-focused strategies when necessary to deal with the repercussions of their child's ABI. Since the amount of perceived instrumental support was high for parents, they were able to express their emotional responses to the ABI without having to worry about whether or not practical support was available to help directly deal with the situations as they arose. Thus, the controllable aspects of the situations were dealt with through the use of instrumental support, and the parents coped using emotion-focused strategies.

Family Environment

The parent's perceptions of their family environment were assessed in 10 areas of family functioning: cohesion, expressiveness, conflict, independence, achievement orientation, intellectual/cultural orientation, active/recreational orientation, moral/religious affiliation, organization and control (Moos, 1974). Mothers and fathers did not differ on their perceptions on any of the areas of family functioning assessed by the Family Environment Scale.

A significant positive relationship between family cohesion and perception-focused coping was found when the relationship between family environment and coping was investigated (refer to Table 7). Parents in the study who utilized perception-focused coping described their family environment as cohesive, or parents who viewed their family unit as cohesive, engaged in coping strategies directed at altering the perception of the ABI.

Studies of parents of pediatric cancer patients have examined characteristics of families that enabled positive adaptation and adjustment. In one study, cohesive (committed and supportive), flexible families tended to do better than enmeshed (overinvolved), disengaged (unconnected families) in the typical situations faced by families with cancer (Chesler & Barbarin, 1987). Another investigation showed that the family relationship dimensions of cohesion and expressiveness most consistently predicted the psychological and social adjustment of children and families with newly-

diagnosed cancer over a 9-month period after initial diagnosis (Varni, Katz, Colegrove & Dolgin, 1996).

Similar findings have been reported in the literature surrounding childhood disability. Family characteristics such as cohesion, integration and adaptability seem to make families more resistant to crisis and more able to adapt to crises (McCubbin et al., 1980; Minnes, 1988; Minnes et al., 1989; Minnes et al., 2000; Nihira et al., 1980; Olson et al., 1979). Adaptability and cohesion have been described as the two dimensions of family flexibility (Olson et al., 1979).

The finding of the positive relationship between perception-focused strategies and family cohesion supports the literature cited above, which suggests that families who are most successful in adapting to the challenges of pediatric cancer and childhood disability are those who are intact and more cohesive than those with poorer outcome. A child with a disability may necessitate many changes in a family's lifestyle (Koch, 1985). If the family does not respond to the need to change, this may become an additional source of stress (McCubbin & Patterson, 1983).

As well, the finding of the relationship between perception-focused coping strategies and family cohesion is consistent with other ABI investigations (Rivara et al., 1996; Thompson, 1997). These studies found that families who were more cohesive, and had a more positive belief system were most successful in adapting to the outcomes of pediatric ABI. The parents' perceptions of their family environment as a cohesive unit in

this study, therefore, may have enabled them to cope more adaptively with their child's injury.

Parental perceptions of their family environment as cohesive may have been influenced by their high ratings of marital satisfaction. Fathers and mothers did not differ significantly from each other in their ratings of marital satisfaction on the measurement scale. In fact, Pearson correlation analysis yielded a significant strong positive relationship between maternal and paternal marital satisfaction, suggesting that both parents rated their satisfaction levels similarly. Thus, if parents viewed their satisfaction with their partner relationship as high, it would contribute to their perceptions of their family environment as being cohesive, since their partnership was strong.

Limitations of the Study

The sample size was relatively small. Several selection criteria limited participation in the study. The inclusion criteria of 2 years or under post-injury for the child, as well as 2 parents living in the home (not necessarily biological) limited the size of the possible participant pool. In particular, the criterion that intact 2 parent families were required for participation in the study significantly decreased the number of eligible participants for the study.

Only 2 parent intact families were used in the study. The study did not investigate coping in single-parent, separated or divorced families, which would have been more representative of families dealing with pediatric ABI. However, by the very fact that the families who did participate remained intact 1.5 to 2 years after the onset of injury, it may be assumed that they have made some degree of adaptation to their changed situation. These families may represent the success stories in the overall population of families with an ABI member.

Eleven of the families who participated in the study reported an income of greater than \$50 000, which is indicative of middle class socio-economic status (Statistics Canada, 1998). An average income for a two-parent family with children is \$54 552, if there is one earner, and \$70 043 for two earners. Thus, the sample consisted mainly of middle-class families, and did not represent low or high socio-economic class families. The availability of income as a resource for the participant families may have affected their dealings with the outcomes of their child's ABI.

Implications of the Findings

The findings of the current study provide some important insight into parental coping following onset of pediatric acquired brain injury, and have a number of implications for rehabilitation theory, practice and research.

Theory

This study provides support for coping theory in 3 respects. First, the divisions of coping put forth by Pearlin & Schooler (1978) are supported by the results of this study. The divisions of coping, namely problem-focused, perception-focused and emotion-focused coping proposed by Pearlin & Schooler (1978) are supported by the findings of the current study. The prominent types of coping strategies used by the parents of pediatric ABI children were perception-focused strategies. The subdivision of the traditional category of emotion-focused coping (Lazarus & Folkman, 1984) into perception-focused and emotion-focused coping allowed for the distinction to be made in this study between the strategies that controlled the meaning of the situation (perception-focused) and those that controlled the emotional response itself (emotion-focused).

Second, the intraindividual or state approach to coping assessment is also supported by this study. The findings of this study suggest that ABI is a unique context and, therefore parental coping was influenced by the specificity of the ABI context. These findings support the intraindividual approach to coping assessment, which suggests

that coping is a dynamic process, showing little consistency both across and within stressful situations (Folkman & Lazarus, 1980, 1985). The coping strategies used in the context of ABI in this study were different than those outlined in the pediatric cancer literature, lending support that coping should be assessed using context-specific methodology.

Last, the findings of the study lend support to the goodness of fit hypothesis outlined by Folkman, Schaefer and Lazarus (1979). The high use of perception-focused strategies by parents in this study may offer support to the goodness of fit hypothesis outlined by Folkman & Lazarus (1979). The goodness of fit hypothesis states that if an event is appraised as controllable, then adaptation will be facilitated by attempts to manage the situation (problem-focused strategies); however, if the event is appraised as having little potential for control, then high levels of adaptation will be associated with the use of strategies to control the emotional reaction to the event (emotion-focused coping). In order to deal effectively with the outcomes of their child's ABI, parents in the study consistently altered their perception of the situation. Controllable situations were dealt with by professionals and by the parents. Day to day positive adaptation was maintained by high use of perception-focused coping. A positive outlook in the midst of uncontrollable situations in this study offers support to the goodness of fit hypothesis.

Practice

The findings of the current study have important implications for clinicians and service providers working with families and children with ABI. Discharge of the child from rehabilitation marks the beginning of a process whereby many parents assume all of the roles of the interdisciplinary team members (Douglas & Spellacy, 1996). They do so frequently with minimal training and support.

“They are the cleaners, the nurses, the physical therapists, the occupational therapists, the communication specialists, the counselors, the attendant carers, the legal representatives, and frequently the targets for aggressive outbursts, as well as the moms and dads of their injured loved ones. They are the mainstays of their families. Their need for ongoing practical and emotional assistance must be met if rehabilitation is going to result in successful integration for their children with ABI who return home.”
(Douglas & Spellacy, 1996, p.836).

Parents are significant determinants of their child’s adaptation to ABI. Assisting parents to positively cope with their child’s ABI, will promote the adaptive adjustment of their child to the outcomes that result from the ABI. Services should be provided to assess the coping repertoire of parents following onset of pediatric ABI. Determination of coping strategies will allow for service providers to make recommendations and suggest alternative methods of dealing with the outcomes of the ABI. Parents can be made aware of their coping style, as well as that of their partner and hopefully, come to understand the implications of each method of coping. Clinicians should promote perception-focused strategies, and encourage a positive way of thinking when dealing with the parents. As well, clinicians should highlight the importance of social support,

and in particular instrumental support, as a coping resource for parents. Parents should also recognize the importance of the family environment as a factor in the adjustment process to ABI. Specifically, the perceptions of family cohesion as a moderator of positive adaptation should be addressed. Increasing parents' awareness of coping, and its effects on adaptation to ABI, as well as facilitating positive coping efforts should be a priority for clinicians working in pediatric ABI rehabilitation. Through the efforts of clinicians and parents working together, the likelihood of positive outcomes for families should increase, and in doing so, lower the negative affects of pediatric ABI including divorce, which is unfortunately so common following this diagnosis.

Research

Parental coping and its repercussions on family adjustment following pediatric acquired brain injury is an area where further investigation is needed. The findings of the present study support pediatric ABI as a unique context, differing from other childhood traumas with respect to its effects and outcome for families. Many conceptual issues in assessing parental coping and family functioning require consideration before commencing future research in this area.

This study used cross-sectional methodology to examine the coping strategies of parents within two years post-injury. Longitudinal investigation of parental coping from onset of injury will provide insight into the coping process (which by definition is variable), and highlight the changes in coping strategies used by parents (if any). Future

longitudinal studies will aid in distinguishing between acute parental reactions and chronic concerns. Acute coping strategies may revolve around issues such as hospitalization, treatments and disruption of normal family routine. Chronic coping strategies may focus on maintaining or returning to normal family life and promoting autonomy for all family members. By noting the point in the recovery process, suitable time-related interventions may be developed.

The present study investigated the parental coping strategies of 2 parent, intact families. Future studies need to incorporate the examination of different parent and family population groups. In order to represent the population of families with a child with ABI, the coping strategies of single-parent, separated and divorced families must be included in studies. The inclusion of all combinations of family types will allow for the relationship between family type and coping strategies to be made. Identification of the effects of family type on coping strategies of parents following ABI will permit clinicians to develop interventions appropriate for each individual family type, enabling positive adjustment.

Continuation of the investigation into the extent to which factors affect parental coping is also warranted. Parental resources, including characteristics of individual parents (education, physical health, psychological adjustment), the family unit as a whole, and the broader social environment (social support, therapy, rehabilitation services) all need to be examined within the context of parental coping following pediatric ABI. The developmental stage of the child, as well as the child's birth order

also may affect parental coping. Last, partner satisfaction and parental relationships with the non-injured children in the family should be investigated to determine their influence on parental coping.

Conclusion

In summary, this study has provided insight regarding the coping strategies used by parents of children with ABI, the relationship between maternal and paternal coping and the affects of social support and family environment on parental coping. The 2 parent intact families investigated by this study prominently used perception-focused strategies to deal with the outcomes of their child's condition. Alterations of the perceptions of their child's ABI were the most commonly reported coping strategies. Mothers had a more extensive coping repertoire than did fathers, using coping strategies more often when compared to fathers. The suggestive nature of the relationship between maternal and paternal coping was complementary. In some cases, when one parent employed a coping strategy, the other did not. The relationships between emotion-focused coping and instrumental support, along with perception-based coping and family cohesion, were strong and positive, highlighting the importance of support and family environment in parental dealings with pediatric ABI.

Parents assume many roles and responsibilities following discharge of a child with acquired brain injury into the community. To effectively cope, clinical intervention with parents is necessary. Parents deserve thorough assessment in order to aid their child

and family to achieve optimal functioning. By positively modifying the behaviors of parents, the likelihood of positive adjustment, as experienced by the entire family may be increased. Clinicians need to help parents to recognize and understand parental coping styles, and enhance the development of positive strategies, including perception-focused strategies, as well as underscoring the importance of social support and the family environment in successful adaptation. Only then can appropriate intervention be implemented, and the reduction of serious dysfunction within the family system which unfortunately is so common following ABI, be lowered.

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Appendix A: Ways of Coping Scale

WAYS OF COPING SCALE(adapted from *Ways of Coping Questionnaire*, Folkman & Lazarus, 1988; revised by McColl & Skinner, 1991)

Below is a list of ways that people cope with difficult situations. Think about a particular difficult situation that you have faced in the past year related to your child's injury. Please describe the situation in a couple of sentences:

Now read each item below and indicate whether or not you used that approach in that difficult situation.

When faced with the difficult situation I described above related to my child's injury I	Not at all (0)	Used some what (1)	Used quite a bit (2)	Used a great deal (3)
1. Talked to someone to find out more about the situation.	()	()	()	()
2. Looked for the silver lining; tried to look on the bright side of things.	()	()	()	()
3. Turned to work or substitute activity to take my mind off things.	()	()	()	()
4. Made a plan of action and followed it.	()	()	()	()
5. Told myself things that helped me feel better.	()	()	()	()
6. Tried to get the person responsible to change his or her mind.	()	()	()	()
7. Talked to someone who could do something concrete about the problem.	()	()	()	()
8. Was inspired to do something creative.	()	()	()	()
9. Tried to keep my feelings to myself.	()	()	()	()

When faced with the difficult situation I described above related to my child's injury I....	Not at all	Used some what	Used quite a bit	Used a great deal
	(0)	(1)	(2)	(3)
10. Changed something so things would turn out right.	()	()	()	()
11. Changed or grew as a person in a good way.	()	()	()	()
12. Expressed anger.	()	()	()	()
13. Stood my ground and fought for what I wanted.	()	()	()	()
14. Came out of the experience better than I went in.	()	()	()	()
15. Let my feelings out somehow.	()	()	()	()
16. Drew on my past experiences; I was in a similar situation before.	()	()	()	()
17. Maintained my pride; kept a stiff upper lip.	()	()	()	()
18. Got away from it for a while; tried to rest or take a vacation.	()	()	()	()
19. Knew what had to be done, so doubled my efforts to make things work out.	()	()	()	()
20. Rediscovered what is important in life.	()	()	()	()
21. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication.	()	()	()	()
22. Came up with a couple of different solutions to the problem.	()	()	()	()
23. Asked a relative or friend I respected for advice.	()	()	()	()

When faced with the difficult situation I described above related to my child's injury I....	Not at all	Used some what	Used quite a bit	Used a great deal
	(0)	(1)	(2)	(3)
24. Avoided being with people in general.	()	()	()	()
25. Went over in my mind what I would say or do.	()	()	()	()
26. Accepted it, since nothing could be done.	()	()	()	()
27. Kept others from knowing how bad things were.	()	()	()	()
28. Thought about how a person I admire would handle this situation and used that as a model.	()	()	()	()
29. Prepared myself for the worst.	()	()	()	()
30. Made a promise that things would be different next time.	()	()	()	()
31. Reminded myself how much worse things could be.	()	()	()	()

Appendix B: Types of Support Questionnaire

TYPES OF SUPPORT

I.D. _____

(adapted from Interpersonal Support Evaluation List, Cohen et. al., 1985; revised by McColl & Skinner, 1991)

For each statement below, please indicate if it is always true about you, usually true, sometimes true or never true about you. Try to decide quickly which answer is most correct about you. Please remember that this is not a test and there are no right or wrong answers.

INSTRUMENTAL SUPPORT

	Always True (3)	Usually True (2)	Some-times (1)	Never True (0)	N/A (9)
1. If I had to go out of town for a few weeks, I know I could find someone to look after my home/plants/pet/etc.					
2. If I needed a quick emergency loan of \$100, there is someone I could get it from.					
3. If I were sick, there is someone who would help me with my daily chores.					
4. If I had to mail an important letter at the post office by 5:00 and couldn't make it, there is someone who could do it for me.					
5. There is someone who would help with minor home modifications or repairs.					
6. There is someone who would help with personal care if I needed it (eg., bathing, dressing, toileting).					
7. There is someone who helps with outdoor chores and heavy work when I need it.					

INFORMATIONAL SUPPORT

- 8. There is someone who can give me good financial advice.
- 9. When I need suggestions for how to deal with a personal problem, there is someone I can turn to.
- 10. There is someone who can give me objective feedback about how I'm handling things.
- 11. There is someone I could turn to for advice about my work.
- 12. There is someone who I feel comfortable going to for advice about sexual problems.
- 13. There is someone I can ask for information or advice related to my child's injury/disability.

Always True (3)	Usually True (2)	Sometimes (1)	Never True (0)	N/A (9)

EMOTIONAL SUPPORT

- 14. There are people who invite me to do things with them.
- 15. I know people who enjoy the same things that I do.
- 16. If I wanted to go out of town for the day, I could find someone to go with me.
- 17. People I know accept me as I am.
- 18. There is at least one person who really understands me.
- 19. I receive moral support and encouragement from a friend or family member.
- 20. There is someone with whom I can share my most private worries and fears.
- 21. There is someone who can cheer me up when I feel down.
- 22. There is someone who takes pride in my accomplishments.

Always True (3)	Usually True (2)	Some-times (1)	Never True (0)	N/A (9)

23. How satisfied are you with the advice and information that you receive from others?

Very satisfied

Not satisfied at all

10 ————— 5 ————— 1

24. How satisfied are you with the practical help you receive from people?

Very satisfied

Not satisfied at all

10 ————— 5 ————— 1

25. How satisfied are you with the emotional support you receive from people?

Very satisfied

Not satisfied at all

10 ————— 5 ————— 1

Appendix C: Family Environment Scale

FAMILY ENVIRONMENT SCALE
 (Adapted from Moos, 1974)

Below are a series of statements that describe different family interactions, atmospheres and emotions. Please mark each statement either true or false, making sure it applies to your family. Remember this is not a test, and there are no right or wrong answers.

	True	False
1. Family members really help and support one another.	()	()
2. Family members often keep their feelings to themselves.	()	()
3. We fight a lot in our family.	()	()
4. We don't do things on own very often in our family.	()	()
5. We feel it is important to be the best at whatever you do.	()	()
6. We often talk about political and social problems.	()	()
7. We spend most weekends and evenings at home.	()	()
8. Family members attend religious services fairly often.	()	()
9. Activities in our family are pretty carefully planned.	()	()
10. Family members are rarely ordered around.	()	()
11. We often seem to be killing time at home.	()	()

	True	False
12. We say anything we want to around the home.	()	()
13. Family members rarely become openly angry.	()	()
14. In our family, we are strongly encouraged to be independent.	()	()
15. Getting ahead in life is very important in our family.	()	()
16. We rarely go to lectures, plays, or concerts.	()	()
17. Friends often come over for dinner or to visit.	()	()
18. We don't say prayers in our family.	()	()
19. We are generally very neat and orderly.	()	()
20. There are very few rules to follow in our family.	()	()
21. We put a lot of energy into what we do at home.	()	()
22. It's hard to "blow off steam" at home without upsetting somebody.	()	()
23. Family members sometimes get so angry they throw things.	()	()
24. We think things out for ourselves in our family.	()	()
25. How much money a person makes is not very important to us.	()	()
26. Learning about new and different things is very important in our family.	()	()

	True	False
27. Nobody in our family is active in sports, Little League, swimming, etc.	()	()
28. We often talk about the religious meaning of Christmas, Passover, or the other holidays.	()	()
29. It's often hard to find things when you need them in our household.	()	()
30. There is one family member who makes most of the decisions.	()	()
31. There is a feeling of togetherness in our family.	()	()
32. We tell each other about our personal problems.	()	()
33. Family members hardly ever loose their tempers.	()	()
34. We come and go as we want in our family.	()	()
35. We believe in competition and "may the best person win."	()	()
36. We are not that interested in cultural activities.	()	()
37. We often go to movies, sports events, camping, etc.	()	()
38. We don't believe in heaven or hell.	()	()
39. Being on time is very important in our family.	()	()
40. There are set ways of doing things at home.	()	()

Appendix D: Correspondence, Consent Forms & Information Sheet

Peter G. Rumney, MD, FRCPC
Physician Director: Neuro Rehabilitation Program
Tel.: (416) 753-6068 Fax: (416) 494-6621
Email: prumney@bloorviewmacmillan.on.ca

Letter of Introduction for Research Study by Kelly Benn

Dear Parents & Clients of the Neuro Rehabilitation Program

This is a brief letter introduction regarding the Research Study being conducted by Ms. Kelly Benn, a rehabilitation student from Queen's University in Kingston. Ms. Benn is actively involved in doing some research working with families who have children who have recently sustained an acquired brain injury (that is, within the last 2 years).

With this letter, we are including the information package with a description of this research as well as some contact information regarding Ms. Benn and her studies.

Participation in this program is entirely voluntary. The research questionnaire may be completed if you wish to participate after you have read through the package. Your involvement in this project or your option to decline involvement will have no effect whatsoever on your involvement with the Neuro Rehabilitation Program here at the Centre.

If you do not wish to participate in this and do not wish to receive a phone call from Ms. Benn, then, by all means, please feel free to contact my secretary (Tom Anderson) at 416-753-6019 or 1-800-363-2400 ext 6019 or you may contact our clinical co-ordinator, Ms. Bev Hachey, at 416-753-6072 or 1-800-363-2440 ext 6072.

If, however, you might be interested, then Ms. Benn will contact you directly by phone in the next few weeks.

Thank you for your attention in this matter.

Sincerely

Peter G. Rumney, MD, FRCPC

**Child Development Centre
Hotel Dieu Hospital
166 Brock Street
Kingston, Ontario
(613) 544-3400 ext. 3175**

2000 April 5

Dear Parents,

The School of Rehabilitation Therapy at Queen's University is conducting a research project to better understand the experiences of families who have a child with an acquired brain injury. The Child Development Centre was asked to help identify any families who may be interested in participating in the study. The study will also include families from the Bloorview MacMillan Centre in Toronto and from Thunder Bay. The research study is part of a master's thesis for Kelly Benn. Ms. Benn and her supervisor, Dr. Mary Ann McColl.

If you agree to participate in the study, each parent would be interviewed by telephone (would take about 30 minutes) and would be asked to complete a brief information sheet. The information is confidential and will not be shared with anyone outside of Ms. Benn's research group. The overall results and trends will help professionals, such as the ABI team at the CDC, to learn about particular stresses and coping strategies in order to help the families more effectively.

The research project is seeking families with children who have experienced a brain injury within the past two years. If you do not want to participate and you would prefer that Ms. Benn did not contact you, please call Marjory Phillips (544-3400 ext. 3191) by Thursday April 20, 2000 in order to take your name off the list. After April 20 2000, I will assume that I have your consent to provide Ms. Benn with a list of the names and phone numbers of the eligible CDC families. This does not mean that you are committed to participate. It simply means that Ms. Benn will call you to ask if you are interested.

Any questions please do not hesitate to contact me.

Thank you in advance for your assistance,

Marjory Phillips, Ph.D,C.Psych

PARENTAL COPING FOLLOWING ONSET OF CHILDHOOD BRAIN INJURY

Funded by an Ontario Government Graduate Scholarship in Science and Technology and
the Bloorview Childrens Hospital Foundation

September 1999- August 2000

CONSENT FORM

Title of Study: Parental Coping Following Onset of Childhood Brain Injury.

Investigators: Kelly Benn, MSc Candidate,
School of Rehabilitation Therapy, Queen's University,
Kingston, ON, CANADA
1-613-533-6815 or 1-877-834-1427 (Toll Free)

Mary Ann McColl, PhD, Professor,
School of Rehabilitation Therapy, Queen's University
1-613-533-6319

Purpose of the Study

What is this study about?

In this study, we want to learn how parents cope after their child has a brain injury. We are asking you if you want to participate. We hope to learn more about the ways parents cope after their child's injury. We also hope to learn about things that may affect the way parents cope. The new information will help to design better services for those parents. By helping the parents, we will also help the children.

Description of Study

What am I asked to do?

This study involves a two-step process.

Step One

The attached letter from Dr. Rumney describes this study. It asks you if you want to participate. Kelly Benn will call you after you have read Dr. Rumney's letter. She is doing the study. She will explain it to you again,

PARENTAL COPING FOLLOWING ONSET OF CHILHOOD BRAIN INJURY

**Funded by an Ontario Government Graduate Scholarship in Science and Technology and
the Bloorview Childrens Hospital Foundation**

September 1999-August 2000

when she calls. She will ask you if you want to participate. If you do, you will be asked to sign this consent form. You can then mail it to us in the envelope provided. We will mail a copy of this form back to you for your records.

A blue information sheet is also included with this form. Please fill it out and send it back with this form.

Step Two

Each parent will have a telephone interview. The interviews will be scheduled separately, when it is best for you. The phone interview will last between half an hour and an hour. During the interview, you will be asked questions about how you cope on a day to day basis. It would be best if you could use a telephone that is in a quiet area. This will free you from distractions.

Please don't talk to your partner about your answers until both of you have done the interview.

Participation

There are no known risks involved in participating in the study. Participation in this study is voluntary. If you want, you can quit from the study at any time. Your decision to stop will not affect your child's future treatment.

Confidentiality

All of the information, which we collect, about your child and yourself will be kept confidential. Your name will not be used in the study. The information you give us will be added to information from about 60 other people. You will be assigned an identification number. Your name will not appear anywhere on our files. Study files will be kept in a locked filing cabinet, at Queen's University. Only study personnel have access to this room. No information about your child or yourself will be given out to anyone without your written permission, *unless this information is required by law*. For example there is the legal duty to report particular infections that could spread to others. It is the law that professionals must report a suspicion of child abuse.

PARENTAL COPING FOLLOWING ONSET OF CHILHOOD BRAIN INJURY

**Funded by an Ontario Government Graduate Scholarship in Science and Technology and
the Bloorview Childrens Hospital Foundation
September 1999-August 2000**

Research information is normally destroyed after the research is done. If it is important to keep research information longer, we will ask for your written consent again. You have the choice of giving or not giving this consent.

For Questions and Further Information

Please do not hesitate to contact Kelly Benn at (613) 533-6815 in the Kingston area, or (877) 834-1427 (toll free) or Mary Ann McColl, PhD., at (613) 533-6319. Your questions can be answered Monday to Friday anytime. If you reach voice mail, please leave your name and phone number. Your call will be returned within 24-48 hours. Alternatively, you can contact Dr. Rumney, locally, at (416) 425-6220 ext. 6019 or 1-800-363-2440, and ask for ext. 6019 (toll free).

Summary of Results

At the end of the study, you will be mailed a summary of the findings. Feel free to contact Kelly Benn at the numbers listed above if you have any comments or questions at that time.

**PLEASE COMPLETE THE CONSENT PORTION OF THIS
FORM ON THE NEXT PAGE.**

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WRITTEN CONSENT FORM

I have taken part in research at this Centre in the past.

Yes No

I am currently participating in another research study at this Centre.

Yes No

The name of this study is

I have read and understood the consent form. I have had the study explained to my satisfaction. I have had my questions about it answered. I understand that I may refuse to participate or withdraw at any time without any penalties of any kind. I agree to participate by completing this form, the information sheet, and a half an hour to an hour interview.

Please Print

Participant #1 Name: _____

Participant #2 Name: _____

Address: _____

Phone No.: _____

Participant #1 Signature

Date

Participant #2 Signature

Date

Investigator's Signature

Date

PARENTAL COPING FOLLOWING ONSET OF CHILDHOOD BRAIN INJURY

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September 1999-August 2000

INFORMATION SHEET

Principal Investigator: Kelly Benn, MSc Candidate,
School of Rehabilitation Therapy,
Queen's University, Kingston, ON, CANADA

Co-Investigator: Mary Ann McColl, PhD, Professor,
School of Rehabilitation Therapy, Queen's University
1-613-533-6319

We are currently involved in a study funded by the Ontario Graduate Scholarship Foundation and the Bloorview Childrens Hospital Foundation, aimed at developing a better understanding of the coping strategies used by parents of children with an acquired brain injury. The study involves two parent families such as yours, whose child has experienced a brain injury in the past two years. Through this study, we hope to learn more about the types of coping strategies parents use following the onset of their child's injury, and the factors that affect those coping strategies. It is hoped that the information will be of use to health care professionals in providing services to parents of children with brain injuries, as well as to the children themselves in aiding family functioning following brain injury.

We would be very grateful if you would help us with this study.

If you did agree to participate, we would ask you to:

- 1. Sign the enclosed consent form; retain one copy for your files and return the two signed copies to us in the self-addressed, stamped envelope provided;**
- 2. Be interviewed, individually, once over the phone, by a specially trained interviewer, who would record your observations and impressions. The interview would take about an hour of your time, and would be scheduled to accommodate you. The interviewer would ask you about your coping styles, psychological issues and your impressions of your family environment;**
- 3. Complete a questionnaire, either over the phone at the time of the interview, or on your own, and return it to us in an envelope provided.**

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the Bloorview Childrens Hospital Foundation
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There are no risks involved in participating in the study. Your participation would be strictly voluntary, and you could withdraw from the study at any time should you wish to do so. Your decision to withdraw will not affect any current or future relationship you might have with the investigators or with any other service providers.

Your name will not be used in the study, and the information you give us will be combined with information from about 30 other people. You will be assigned an identification number, which will be used on our study records, and your name will not appear anywhere on our files. Study files will be kept in a locked filing cabinet in the Research Room at the School of Rehabilitation Therapy at Queen's University. Only study personnel have access to this room.

**One of the enclosed copies of the information sheet and consent form is for you to keep, in case you need to refer to it in the future. If at any time you have any questions about the study, I urge you to refer them to me, Kelly Benn, the principal investigator, or Dr. Mary Ann McColl. Alternatively, you could contact Dr. Sandra Olney, Director of the School of Rehabilitation Therapy at Queen's University
(1-613-533-6102).**

Thank you in advance for considering this request.

Sincerely,

Kelly Benn, MSc Candidate

Date: _____

PARENTAL COPING FOLLOWING ONSET OF CHILDHOOD BRAIN INJURY

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the Bloorview Childrens Hospital Foundation
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CONSENT FORM

Principal Investigator: Kelly Benn, MSc Candidate, School of Rehabilitation
Therapy, Queen's University, Kingston, ON, CANADA

Co-Investigator: Mary Ann McColl, PhD, Professor, School of
Rehabilitation Therapy, Queen's University
1-613-533-6319

**I have read and understood the attached information sheet. I have had the
study explained to my satisfaction, and have had my questions about it answered.
I understand the nature and extent of my participation, and I agree to
participate by completing a questionnaire and a one hour interview.**

Participant Name: _____

Address: _____

Phone Number: _____

Participant signature

Date

Witness signature

Date

Investigator signature

Date

**YOU MAY KEEP A COPY OF THE INFORMATION FORM AND THE CONSENT
FORM FOR FUTURE REFERENCE.**

**IF YOU HAVE ANY QUESTIONS, PLEASE CONTACT:
KELLY BENN, QUEEN'S UNIVERSITY 1-613-533-6319**

