MATERNAL CAREGIVING THROUGHOUT THE LIFESPAN:
AN ETHNOGRAPHIC STUDY OF THE EXPERIENCES OF MOTHERS OF ADULT
CHILDREN WHO SUSTAIN TRAUMATIC BRAIN INJURY

by

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B.S.N., The University of Victoria, 1991

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
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in

THE FACULTY OF GRADUATE STUDIES

(The School of Nursing)

We accept this thesis as conforming
to the required standard

The University of British Columbia

May, 1998

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Department of School of Nursing
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Date May 26, 1999
Abstract

The survival rate of persons who sustain traumatic brain injury (TBI) continues to increase due to recent technological advances in emergency medicine, and use of helmets and seat belts. The survivors, who are often young adults, generally return to their family of origin to receive the care they need. Although it is widely acknowledged that TBI impacts on these families, particularly the mothers who play a crucial role in the caregiving, little is known about the changes that occur in the mothers' lives. The purpose of this study was to further understand the experiences of mothers whose lifespan expectations are altered when they become primary caregivers to their previously independent adult children. Using the ethnography method and drawing from Ryan's (1993) a "Lifetime of Mothering" conceptual framework as a basis to collect the data, constant comparative analysis was used to analyze the data. This approach resulted in a descriptive analysis that conveyed a common conceptualization of the experience.

Participants were obtained through the British Columbia Brain Injury Society, Greater Victoria Hospital Society (now known as the Capital Health Region) and the "snowball" technique. Of eight mothers who were interviewed, six fit the criteria of the study. Interviews were one to two hours in length. Of the six mothers, length of time post-injury ranged from 3 years nine months to 11 years, the average length of time was 7 years 6 months. Four of the adult children were female. At the time of the interviews, three adult children with TBI lived in their mothers' homes, two had just started to live independently, and one lived in close proximity.

The data analysis yielded the core category "The Experience of Enduring". The central components of the mothers' descriptions of Enduring were the processes of Becoming a Caregiver, Grasping Reality and Carrying Responsibility. Although each mother's situation
was found to be unique, three major Tactics were used by all when Enduring the Experience that included: Pulling from Within; Comparing in Order to Put a Face On It; and Dealing With It. Dealing With It involved Inside Work and Outside Work. Inside Work encompassed activities directed at holding the mothers and their family together. Outside Work entailed activities dealt with outside the home that were directly related to the caregiving experience. The uniqueness of each mother's situation was influenced by three Intervening Conditions: Mothers' Individual Ways; Availability of Services; and Economic Influences. As a consequence of Enduring The Experience, all of the women experienced both Gains and Losses. These outcomes had a direct bearing on their Experience of Enduring.

Mothers lives are permanently affected by the caregiving experience. The constant caregiving without adequate resources is particularly onerous. Ongoing caregiving of children with TBI has consequences which are both positive and negative. Mothers with TBI caregiving responsibilities over time develop strategies for coping.

Based on the findings of the study, implications for nursing practice, education, and research were identified to provide nurses with the knowledge and skills to render support to these ongoing caregivers.
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I thank Kathy Ryan for permitting me to adapt and use her conceptual framework for this study.

I appreciate the assistance and enthusiasm from various groups and individuals who assisted me to locate participants.

I am extremely grateful to the mothers who so eagerly participated. Their sharing of their experiences touched me deeply and provided me with a new perspective and deeper understanding of the devotion, commitment and love that caregiving mothers have for their children when they sustain traumatic brain injury.

Finally, I would like to thank my family and friends for their gifts of love, caring, patience and understanding. I especially thank my husband Sus whose constant encouragement kept me going along the way.
CHAPTER ONE

Background to the Problem

The survival rate of persons who sustain traumatic brain injury (TBI) has been increasing due to technological advances in emergency medicine, and use of helmets and seat belts (Carola, 1990; Ivan, 1984). An estimated 20,000 to 25,000 people in Canada (Ivan) and 4,000 people in British Columbia are affected by brain trauma each year (Higenbottam, 1994). Consequently, brain injury is a major health concern of our time.

Individuals surviving substantial brain trauma are left with changes to personality (Brooks, 1991; Brooks & McKinlay, 1983) and devastating, irreversible physical, emotional, cognitive and financial disabilities resulting in the need for ongoing care (DeJong, Batavia & Williams, 1990; Lezak, 1988; McClelland, 1988). Moreover, individuals surviving mild brain trauma have been found to manifest similar deficits and require similar care (Katz & DeLuca, 1992; Lezak; Rosenthal, 1993). Families are expected to provide care once the family member is discharged from emergency settings, acute care or rehabilitation programs, or when money for rehabilitation programs runs out (DeJong et al.; Jacobs, 1988; Kozloff, 1987).

The majority of brain injuries occur in unmarried young adults (Willer, Abosch & Dahmer, 1990) who return to their families of origin to receive the care they need. This care is almost inevitably provided by their mothers (Acorn, 1993; Campbell, 1988; Carson, 1993; DeJong et al., 1990; McLelland, 1988), because women take on the central role in providing care in a family (Aldous, 1994; McGoldrick, 1989). When the survivor is an adult child who had been independent, mothers adaptation to a caretaking role that had been altered, is necessary. Consequently, the usual family development process, which includes changes to
the structure of parental roles in response to children reaching independence in adulthood (Hill & Mattessich, 1979, p. 174), is not realized by these mothers.

Even though mothers' lives are changed as a result of their adult children's TBI, several authors have commented that mothers caring for their adult children who sustain TBI are returning to a previous filled role; therefore, the impact on mothers' lives will be minimal (Florian & Katz, 1991; Kreutzer, Marwitz & Kepler, 1992; Leach, Frank, Bouman & Farmer, 1994; Miller, 1991; Panting & Merry, 1972; Thomsen, 1974). Furthermore, Brooks (1984) stated that some mothers welcomed the childlike behavior in their adult child with a TBI.

Kreutzer et al. (1992) concluded that Panting and Merry's (1972) early study set the stage for future research when they noted that TBI in a family member had a greater psychological impact on spouses of the injured rather than on mothers of the injured. Panting and Merry's findings were reinforced by outcomes of other research (Brooks, 1984; Rosenbaum & Najeson, 1976; Thomsen, 1974, 1984). As a result, most studies that have targeted the impact of brain injury on specific family members have centred on spouses of the injured (Acorn & Roberts, 1992; Anderson-Parente', DeCesare & Parente', 1990; Grinspun, 1991; Kravetz et al., 1995; Moore, Stambrook, Peters & Lubusko, 1991; Peters, Stambrook, Moore & Esses, 1990; Rosenbaum & Najeson; Willer, Allen, Liss & Zicht, 1991; Willer, Arrigali & Liss, 1989; Zeigler, 1989). Because most brain injuries occur in males (Zeigler), the impact of the brain injury on the lives of wives of the injured (Acorn & Roberts; Rosenbaum & Najeson) and their relationships with their injured husbands (Kravetz et al.; Peters et al.; Willer et al., 1989) have been examined. In investigations that have included both husbands and wives of the injured, the husbands' and wives' different experiences have been noted and the need to understand these differences is underscored (Anderson-Parente' et
al.; Willer et al., 1991; Zeigler). Mothers' experiences are included in studies that have addressed families or parents; their experiences have been explored as part of a unit or set (Carson, 1993; Johnson, 1995).

In many studies that have focused on the family as a unit, mothers have made up a major portion of the sample. This scenario is consistent with the literature that addresses chronic illness in children, wherein health professionals refer to the family as caregivers even though mothers have been found to provide that care (Anderson & Elfert, 1989). For example, family studies have centred on determining: (1) family needs during the acute and post acute stage (Campbell, 1988; Kreutzer, Serio & Bergquist, 1994; Mauss-Clum & Ryan, 1981); (2) the relationship between family functioning and successful rehabilitation of the brain injured family member (Kreutzer, Gervasio & Camplair, 1994a, 1994b; Zarski, De Pompei & Zook, 1988); (3) family stress (Hall et al., 1994; Oddy, Humphrey & Uttley, 1978) and (4) family distress (Novack, Bergquist, Bennett & Gouvier, 1991; O'Brien, 1986) related to the caregiving. Attempts by Scottish researchers to identify family burden associated with the caregiving occurred in both longitudinal (Brooks, Campsie, Symington, Beattie & McKinlay, 1986, 1987) and short-term analyses (McKinlay, Brooks, Bond, Martinage & Marshall, 1981). In addition, members of this team compared the burden experienced by mothers and wives in caring for mild versus severe brain injured family members (Livingston, Brooks & Bond, 1985a). They also compared the burden experienced by mothers and wives of the severely brain injured over the course of a year (Livingston et al., 1985b). The percentage of mothers participating in these studies is presented in Table I.
### Table I

Percentage of Mothers Participating in Selected Family Studies Related to Traumatic Brain Injury (TBI) in Family Member

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Note. MO = mothers; SP = spouse; FA = father; SIB = sibling; WI = wives; HUS = husband; REL = relative; SIS = sisters; COUS = cousins; C/O = comparison of.

Percentages have been rounded.

Clearly, mothers have been solidly represented in reported studies that have addressed families of adults with TBI. However, in many of those studies caution is needed when interpreting mothers' experiences because the data are based on the various members of the family as the primary caregiver. The specific experiences of mothers of children who have sustained TBI have not been explored. Furthermore, Kay, Cavallo, Ezracht and Vavagiakis (1995) posit that brain injury profoundly effects the personal lives of parents and their relationships with other people "not just their relationship to the injured person" (p. 17). For example, the effect on mothers' personal lives is illustrated when many researchers have remarked that mothers have expressed concerns about what will happen to their children when they are no longer there to take care of them (Leaf, 1993; Lezak, 1988; Mauss-Clum & Ryan, 1981; Miller, 1991). The expectations held by society and mothers are that children
will increase in their independence as they mature and will not require maternal caregiving over the lifespan (Greene & Boxer, 1986). However, the lack of reported studies exploring the impact that brain injuries in adult children have on mother's lifespan expectations is conspicuous.

Research Question

This study proposes to answer the following question: What are the experiences of mothers whose lifespan expectations are altered when they are required to become "primary caregivers" to previously independent adult children who re-enter their lives as dependent adult children as a result of a traumatic brain injury?

Definition of Terms

For purposes of this study, the following definition of terms apply:

Mothers: biological (or adoptive) mothers who have provided maternal caregiving to the previously independent adult child with the TBI from infancy to adulthood.

Re-entered: a situation wherein a previous held role is again operationalized.

Lifespan Expectations: a set of expectations held by society and within families that children become independent as they mature resulting in a need for less parental involvement in their lives.

Primary Caregivers: persons who take the responsibility for providing the main caregiving such as day to day care, coordination of services, and advocacy.

Adult Children: offspring (or adoptive children) 19 years of age or older.

Independent: a condition wherein there is no requirement or reliance on others for physical, financial, emotional, social care and/or support.

Dependent: a condition wherein there is an extraordinary need for physical, financial, emotional, social care and/or support.
Traumatic Brain Injury (TBI): a traumatic insult or damage to the brain caused by an 
external force that results in changes to personality, cognitive, affective, or physical 
functioning. In this study, the TBI was sustained at least one year ago.

Experience: personally lived through events (Merriam-Webster, 1977, p.403).

Assumptions

This following assumptions were inherent in this research study:

1. Mothers who become primary caregivers to their previously independent adult children 
   who become dependent following TBI are subject to a unique experience.
2. Mothers are able to describe their experiences with caregiving their adult children with 
   TBI.
3. The information shared by mothers is based on their perceptions of the experience.
4. An understanding of the day-today lives of mothers can be attained through the 
   focused ethnography research method.

Conceptual Framework

Ryan's (1992, 1993) conceptual framework, "A Lifetime of Mothering" was adapted 
with permission for this study (see Figure 1). The framework was derived from a qualitative 
descriptive study that used an ethnographic method of investigation of mothers living with 
adult children with schizophrenia. The central theme of the framework, "A Lifetime of 
Mothering", emerged because the mothers were engaged in active mothering over an 
indefinite period of time. This phenomenon is atypical of mothers of adult children whose 
children become more independent allowing for more maternal freedom (1993, p. 24). The 
central theme is composed of two central constructs "Disruption" and "Loss".
Figure 1. Ryan's (1993) schematic representation of the experience of mothers living with their adult children with schizophrenia.

Note. Enclosure marked by --- = The portion of the framework that is used as a conceptual basis for this study. From "Mothers of adult children with schizophrenia: An ethnographic study" by K. Ryan, 1993, Schizophrenic Research, 11, p.24. Reproduced and adapted with permission.
**Disruption**

The disruption construct was determined because of the interruption and disorder in the day-to-day lives of mothers, as well as the usual life rhythms making "a 'normal' adult [to adult] relationship" between mother and child difficult (Ryan, 1992, p.27). This construct is composed of two components: (1) disruption in the mother’s life, and (2) disruption in the relations between mother and child.

Disruption in the mother’s life is depicted by three characteristics. The first, Constancy, refers to the situation as being ever present and unremitting in nature that is similar to caring for a young child. The second, Centrality, refers to the pivotal role mothers assume in caring for the ill child. The third, Uncertainty, is concerned with the course of the illness (ie. whether the illness would subside), the future (ie. particularly what would happen to the child when the mother was no longer there), and the unpredictability of the illness.

Managing the disruption, both in the relationship between mother and child and in the mother’s life, are factors in this construct. Management of the disruption of the relationship is arrived at by managing illness behaviors, and management of the disruption in the mother’s life includes going from day to day, and getting away. In Ryan's (1992, 1993) framework, specific actions are identified and defined that include accommodating, setting limits and normalizing behavior.

**Loss**

Two components are included in the loss construct: (1) loss of the child’s potential; and (2) loss of freedom for the mother. The loss construct was identified because mothers expressed longing for what might have been had their child not become ill. This inability for the child to achieve adult goals was the reason that mothers were unable to experience the expected increased freedom from caregiving that is usual for mothers of children who reach
adult status (Ryan, 1992, p. 61). Managing loss is a pivotal factor in the framework.

Managing the loss of the child's potential and the mother's freedom are intertwined.

This framework was selected because of specific similarities between mothers who are primary caregivers to adult children who have schizophrenia and mothers who are primary caregivers to adult children who have sustained TBI. Namely, schizophrenia is a disease that most commonly occurs in the young adult population with cognitive and affective functioning being affected; it persists throughout life (Kaplan, Sadock & Grebb, 1994); and mothers are the main caregivers (Chafetz & Barnes, 1989; Maurin & Boyd, 1990). This study addresses TBI in the young adult population whose cognitive and affective functioning are also compromised; the consequence of brain injury has long term effects (Brooks, 1991); and the experiences of mothers who are caregiving will be explored.

Only that portion of Ryan's (1993) Lifetime of Mothering Framework identified in the figure was used to direct the review of the literature and the collection of data. The portions of mother's specific caregiving actions, specific causes of disruption as well as the loss of freedom for the mother were excluded because it was perceived that to include them would have programmed the study more than was wanted.

Statement of the Problem

Historically, clinicians and researchers have recognized that families are the crucial, and frequently the only, caregiving resource for populations with TBI (Panting & Merry, 1972; Romano, 1974). Nevertheless, there is a dearth of research based knowledge that can be used to guide clinical decision making related to helping families who are providing this care (Kreutzer et al., 1992). Currently, there is an increased chronicity related to advances in medical management (Hickey, 1993). But, radical changes to the healthcare system that shifts the paradigm from managing ill family members within institutional settings to
managing them "closer to home" (The British Columbia Royal Commission on Health Care and Costs, 1991), has resulted in many families being expected to be frontline caregivers to their members with other chronic illnesses. As a result, a reshaping of nursing practice is required as pressures and expectations are placed upon families to provide the necessary caregiving. With the refocusing of the delivery of health care, nurses need a knowledge base that will assist them in working with families in a different way. Because mothers are known to be the frontline caregivers in a family, then knowledge about how to help them to become caregivers, and to manage problems and crisis situations is needed. Understanding the experiences of mothers who are caregiving their adult children who have sustained TBI will not only provide a knowledge base for clinical interventions with these mothers, but will also help nurses understand further what is taking place with other caregiving mothers; this knowledge is of utmost importance to nursing practice.

Significance of the Study

The study has significance for nursing practice and nursing theory development. First, the mothers of adult children who sustain TBI are a major caregiving source but little is known about their experiences. These experiences need to be recognized and understood. By gleaning an understanding, nurses will be knowledgable as to how they can provide support in order that the mothers are helped with their valuable efforts. Additionally, the study has significance for nursing theory development. By using the adapted "Lifetime of Mothering" conceptual framework, nursing theory related to lifelong maternal caregiving will be expanded. The model of the Lifetime of Mothering was derived from nursing research. This study will utilize the model with a different population; thus, the development of this theory will be furthered.
CHAPTER TWO
Review of the Literature

Introduction

Because maternal caregiving of a traumatically brain injured adult child is a complex experience involving both mothering and caregiving, this literature review will address broader parameters than afforded by Ryan's (1993) "Lifetime of Mothering Framework". Thus, Ryan's framework was adapted for this literature review resulting in four main categories that include: mothering; caregiving within mothering; burden within caregiving; and caregivers' attempts to manage burden. That is, when the literature was reviewed for mothering and caregiving, these themes evolved. How they are related to the model will be identified. The organization of the literature review is presented (see Figure 2).

To begin this review, mothering, the central theme of the framework is presented. Because there is a plethora of literature on mothering, the review of the literature is limited to a theoretical perspective. In particular, attachment theory was selected (as opposed to feminist or social construct theories), because mothering, the mother-child relationship and caregiving of children are included in the theory. These concepts are considered pertinent for this study. Each will be discussed.

Then, because a lifetime of mothering is associated with the relentless caregiving required by adult offspring with TBI, caregiving literature is reviewed. Given the huge body of literature available about caregiving, selected aspects of this literature will be reviewed and critiqued. Specific literature that addresses caregiving pertaining to mothers who are caregiving adult offspring and mothers who are caregiving adult children who have sustained a TBI will be presented.
Figure 2. Framework of Literature Review.
Following the section on caregiving is a review of the literature about caregiver burden. Again, an overview and critique of this general caregiver burden literature will be provided. Then, caregiver burden literature focused on caregiving mothers of adult children will be given, followed by caregiving burden literature that looks at mothers who are caregiving their adult child with a TBI. For purposes of this literature review, the disruption and loss construct found in Ryan's (1993) framework is considered within the burden literature.

The fourth and final section will include literature that explores caregivers' attempts to manage burden with attention to coping styles. This section will provide the base for the management component of Ryan's (1993) framework. In doing so, this portion of the literature review will be presented under three categories that will include: first, findings from qualitative studies that looked at women's attempts to manage situational burden; second, literature that is focused on mothers' attempts to manage caregiver burden experienced when they are primary caregivers to adult children; and third, literature that addresses mothers' attempts to manage caregiver burden experienced when caregiving their adult children with TBI.

Finally, how the study fits within the literature will be summarized. Gaps and weaknesses within the literature will be noted.

**Attachment Theory**

Attachment theory was first introduced by psychologist John Bowlby in 1969 (Parkes & Stevenson-Hinde, 1982). Bowlby formulated the theory during a 24 year period while working as head of the Childrens' Department at Britain's Tavistock Clinic (Bretherton, 1993). The theory attempted to explain the ties infants had to their mothers and the disruption of that relationship as a result of deprivation and separation. Attachment theory
was further expanded by Mary Ainsworth who contributed the theoretical components of individual differences in attachment, and the conceptualization of the caregiver as a secure base. Major purposes of attachment theory were to guide research that would shed a light on "attachments and other affectional bonds beyond infancy" (Ainsworth, 1993, p. 48), as well as to promote the understanding of interpersonal relationships, and primarily parent-child attachment (Bowlby, 1988). Attachment theory has been subjected to an immense amount of research (Bowlby, 1988), and the scrupulous scientific rigor that the theory has undergone is well documented (Parkes & Stevenson-Hinde, 1982, 1993). Although still being continuously tested and developed (Bretherton, 1993), the theory provides a base for the understanding of mothering, mother-child attachment and mothers as caregivers.

The basic premise of the theory is that there is an attachment behavioral system within humans which has developed through evolution with protection being its biological function (Bowlby, 1993). This attachment control system monitors relevant events and appraises them as to whether they are dangerous and threatening (Bowlby, 1982). If events are perceived as dangerous and threatening, then, as a system it seeks to maintain homeostasis (Bowlby, 1982) by selectively responding only to a small number of familiar caregiving figures (Bretherton, 1985). These responses are distinct from dependency and are not indicative of bonding nor regression; instead, they are considered to perform a natural, healthy function even in adult life (Bowlby, 1982). The attachment control system is assembled in the mind during childhood, and the link between self and attachment figures remains throughout life as a central feature of personality functioning (Bowlby, 1988).
Included within the theory is a conceptualization of attachment behavior defined by Bowlby (1988) as:

"any form of behavior that results in a person attaining or maintaining proximity to some clearly identified individual who is conceived as better able to cope with the world" (p. 26).

This behavior is episodic in nature, because it is particularly evident during times of fright, fatigue, or sickness when it is alleviated by comforting and caregiving, while at other times it is less obvious. Also embraced by attachment theory are the enduring attachments such as those made by children and individuals to others.

According to Bowlby (1993), attachment strategies in the young have evolved only because of responsive caregiving strategies of parents. These parenting behaviors are considered to be strongly rooted in biology (Bowlby, 1988). When viewing mothering within attachment theory, it is presumed that attachment in offspring is complemented by maternal caregiving strategies. Children attached to mothers seek closeness when they are ill, tired, and/or frightened (Bowlby, 1982). These attachment behaviors have an enduring quality, are unaffected by momentary situations (Bowlby, 1982), and although they are "most obvious during early childhood", they tend to be present throughout the life cycle (Bowlby, 1988, p. 27). Providing children with caregiving when needed is considered appropriate mothering behavior, and this pattern tends to continue throughout the child's adult life (Bowlby, 1982).

Several factors pertain to the mother-child relationship when applying attachment theory. First, Ainsworth (1993) noted in her extensive research that even though nurturing and care are eagerly provided through mother-infant bonding, attachment does not necessarily have to develop, and even if it does, different qualities of attachments can occur, such as secure, anxious, or ambivalent. Generally, most mother-child relationships are based on
secure attachments (Ainsworth, 1993). Second, the pattern of attachment that is developed tends to remain throughout the relationship (Ainsworth, 1982). Third, mothers who are sensitive and responsive as attachment figures are enabling their children to develop along a healthy pathway (Bowlby, 1988). A "secure base" is provided for their children to explore the world (p. 140). (Other mothering patterns in regards to caregiving can include humiliation, rejection and criticism.) Fourth, when an attachment figure is both responsive and available, a strong sense of security is provided and persons feel encouraged to "value and continue the relationship" (Bowlby, 1988, p. 27). Fifth, attachment figures can never be replaced or interchanged because an affectional bond exists (Ainsworth, 1993). Emphasis is placed on attachment being part of the affectional bond and not the affectional bond itself (Ainsworth, 1993; Bowlby, 1982). Sixth, in adulthood, even though a new principal attachment figure may be found in a sexual partner, attachment to mothers endures (Ainsworth, 1993). Seventh, the mother-child relationship is not based exclusively on the caregiving role, other roles are included such as playmate (Bretherton, 1985).

When an individual seeks out someone who is regarded as stronger and wiser because they are weaker or less experienced, this behavior is defined as careseeking (Bowlby, 1982). When a child is careseeking from their parents, their behavior can be designated attachment behavior. Mothers who provide caregiving to their careseeking children are enacting their major role as a parent and are complimenting the attachment behavior. Bowlby considered this behavior to be basic to human nature.

Ainsworth (1993) emphasized that little is known about child-parent attachment during adulthood once it has been reached. In particular, the potentiality for role reversal is considered healthy especially if a parent becomes "impaired through illness or old age" (p. 38). Weiss (1993) found through several unsystematic observations and interviews that when
children matured their parents displayed diminished attachment behavior to them. But, when mature children were at risk, "attachment feelings" could be elicited in parents, and a death of a mature child was similarly experienced as a death of a young child (p. 75). In this context, it is implied that attachment is the feelings associated with wanting to provide responsive and sensitive caregiving as necessary, those behaviors that are the earmark of appropriate mothering behavior during childhood. Weiss' comments adds impetus to Bowlby's attachment theory by endorsing the premise that attachment behavior strategies in children with the complimentary caregiving strategies in mothers are present throughout the lifespan.

In summary, the thoroughly and continuously tested attachment theory provides a basis for the understanding of mother-child relationships, and the dynamics of why mothers respond to the careseeking behaviors of their children by caregiving. Attachment theory is built upon the premise that humans have a biologically rooted attachment behavioral system that provides natural human functions around protection: Both the actions of seeking protection from able persons when needed and the complementary action of the giving of protection by those specific persons are included. Within the mother-child relationship, attachment behavior in children is evident when they seek out their mothers when needed, and at those times the complimentary maternal caregiving is provided as necessary. The episodic attachment behaviors within mother-child relationships have characteristics that are distinct to each mother-child relationship, with lifelong patterns that are irreplaceable and enduring even though the attachment behavior diminishes when children grow independent.
Caregiving Role

Caregiving of Elderly Adults

Because caregiving is central to this study, the literature that addresses the functions of the caregiving role that pertains to the caregiving of adults is reviewed. In this regard, the literature that addresses caregiving of adults is focused primarily on females who care for their frail elderly family members (Stone, Cafferata & Sangl, 1987). Because most often either daughters, daughters-in-law or wives take on the caregiving role and become the primary caregivers, they are the major participants in the numerous studies of caregiving that have been reported (Brody, Hoffman, Kleban & Schoonover, 1989; Finley, 1989; Stone et al.; Wright, 1994). The literature abounds with findings about these informal caregivers who deal with the functional dependency of the frail elderly, and particularly, the caregiving of elderly family members with Alzheimer’s disease or dementia (Archbold, 1983; Chenoweth & Spencer, 1986; George & Gwyther, 1986; Lindgren, 1993; Wright). Within nursing research, the principal focus on the female caregiver role has been on daughters and daughters-in-law caring for these functionally disabled elderly (Archbold; Bowers, 1987), and although less extensive, the caregiving role of wives has been examined within this context (Cameron, 1990; Perry, 1996). Behavioral scientists have also examined the female role pertaining to caregiving the elderly (Pearlin, 1992), and have proposed theoretical perspectives (Aldous, 1994; Kahana & Young, 1990). As a result, the caregiving role as it applies to the care of the elderly, has been described and defined in various ways. Literature pertaining to females caregiving their cognitively impaired elderly family members with Alzheimer’s disease or dementia is reviewed in order to place this study within the context of the broader literature.
The activities of the caregiver role are found to be dependent on the needs of the care recipient (Cantor, 1987; King, 1993; Lindgren, 1993; Pearlin, 1992; Stone et al., 1987). Consequently, the caregiver role can become more demanding as the care recipient becomes more dependent (Stone et al.). However, when caregiving elderly cognitively impaired family members, the demands of the caregiving role diminishes when care recipients are institutionalized and ceases when the care recipient dies (Lindgren; Pearlin; Stone et al.). As a result, the caregiver role has been referred to as a career (Lindgren; Pearlin) that encompasses residential caregiving, institutional placement and bereavement (Pearlin), and within the caregiver career, specific stages "Encounter", "Enduring" and "Exit" have been identified (Lindgren).

Within the theoretical literature, the caregiving role is depicted as being concerned, comforting, providing a comfortable environment, "taking charge of" the welfare of the care recipient, and providing financial assistance when needed (Aldous, 1994). Furthermore, according to Kahana and Young (1990), the caregiving role is viewed as being a dynamic relationship between the caregiver and care recipient and that caregiving involves "complex interactions" between the caregiver and care recipient (p. 76). Thus, the caregiving role has the potential for either negative or positive outcomes or consequences for either (p. 76). As a result, the need for clarification about the assumptions of the relationships and the extent of the interactions within the relationship is recommended, otherwise; negative outcomes to the caregiver and care recipient can occur. More explicitly, when there is a 'fit' between the care recipient's needs and the type of care provided by the caregiver, then positive outcomes are realized by both (p. 76). Conversely, when there is a misfit, then, negative outcomes are experienced by both the caregiver and care recipient.
Observable activities of caregiving. In order to discern what the caregiving role entails, caregiver researchers have reported on the observable tasks performed by caregivers for care recipients. These tasks include activities related to administering to the physical needs of the care recipient by providing hands-on care (Archbold, 1983; Bowers, 1987; Lindgren, 1993; Wallhagen, 1992). When providing the hands-on care, the caregiving tasks of acquiring knowledge of and becoming proficient in nursing routines is required (Lindgren). In addition, tasks other than hands-on have been observed as being part of the caregiver role and consist of supervising (Bowers) and/or managing care (Archbold) pertaining to the social and psychological needs of the care recipient (Archbold; Bowers). To accomplish this aspect of the caregiver role, the caregiving activities include becoming knowledgeable about pertinent community resources, evaluating these services, assessing the functional capacities of the care recipient, and then, based on the acquired information, cultivating caring systems by obtaining and retaining appropriate services for the care recipient (Archbold). Also, the devising of activities that will provide enjoyment to the care recipient is reported (Archbold).

Invisible mental activities of caregiving. In addition, caregiver role researchers have identified practices that go well beyond observable task orientations (Bowers, 1987; Lindgren, 1993; Wallhagen, 1992). That is, the caregiving role takes into account the invisible mental activities that are not evident to the care recipient nor to health care teams (Bowers) even though they address the interpersonal and emotional needs and concerns of the care recipient (Bowers; Wallhagen). Towards this end, the activities include making decisions (Bowers) and always having the care recipient's welfare on caregivers' minds (Wallhagen): Both are considered by caregivers to be important and powerful activities of the caregiver role (Bowers; Wallhagen). In doing so, caregivers are required to: make decisions around anticipating and meeting the care recipient's "possible needs"; assume activities that
prevent untoward difficulties for the care recipient such as mental or physical deterioration, illness, or injury; and, most importantly, find ways to protect the care recipient from the unpreventable in order that their self-image is preserved, their personhood and self-esteem is protected, and the relationship between the caregiver and care recipient is maintained (Bowers, p. 26).

In the literature, other invisible aspects of the caregiver role have been highlighted. That is, caregivers are not only compelled to confront diagnosis and loss of a previous lifestyle, and cope with social isolation and "mental pain" (Lindgren, 1993), but they are also required to work through transitions and bereavement (Pearlin, 1992).

In summary, the caregiving role as it relates to the cognitively impaired elderly is held mostly by females. The caregiving role is dependent on the needs of the care recipient. Meeting the caregiving needs of the elderly is a career-like process with a beginning, middle and end stage. An underlying theory about the caregiving role is that it is dynamic and has the potential for positive or negative outcomes for both the care recipient and the caregiver dependent upon the 'fit' between the care given and the care needed. The caregiving role includes both observable activities performed for the care recipient and invisible mental activities that help to anticipate the care recipient's needs, that prevent untoward happenings to the care recipient, and that protect the care recipient's self-image. When taking on the caregiving role, caregivers are required to acquire knowledge and master skills pertinent to the care recipient's needs as well as make decisions, confront diagnosis, provide comfort, sometimes financial assistance, and endure transitions and bereavement.

This section provided an overview of the existing knowledge about the caregiver role as it pertains to females caregiving elderly family members who are cognitively impaired or who have Alzheimer's disease. Although the literature presented in this section provides a
basis for viewing the caregiving role (and how the caregiving role could fit into the mothering role), the findings have to be considered according to the context in which the caregiving took place. Caregiving to an elderly person with dementia or Alzheimer's disease differs substantially from caregiving a younger person with TBI (Carson, 1992). For example, Alzheimer's disease and dementia have an insidious onset whereas TBI is sudden. Alzheimer's disease progressive deterioration is quite different from TBI's constant course and sometimes improvement. Alzheimer's disease can shorten the life span or produce fatal outcomes but TBI is non-fatal once stabilization has been reached. Furthermore, persons with dementia or Alzheimer's disease for the most part are elderly and have lived a normal lifespan, whereas, the persons with TBI addressed in this study are younger and are expected to live a normal lifespan.

Mothering and Caregiving

Because this study addresses mothers who are the primary caregivers of their adult children who sustain TBI, literature that addresses the mothering role and the caregiving function within the maternal role is reviewed.

The mothering role is multifaceted with caregiving being only one aspect. Generally, the role evolves from meeting the child's day to day needs during early childhood (Cavanaugh, 1990), to letting go and providing guidance and support during adolescence (Friedman, 1986), and finally assuming a mutual sharing role (Cavanaugh) or reciprocity (Troll, Miller & Atchley, 1979) once adulthood has been reached. Even during the early childhood stage, the mothering role is not exclusively caregiving and can include such roles as entertainer (Bretherton, 1985), nurturer, and comforter (Ainsworth, 1993), watcher of children's growth, reciprocity of affection, and companion (Stevens & Meleis, 1991). When children become adults, the mothering role can include friend and financial assistant (Troll &
Bengston, 1982), kinkeeper (by keeping adult children in touch with other family members) and supporter (by sharing relevant experiences) (Greene & Boxer, 1986). Although it has been found that during times of children's illnesses mothers take on the caregiving (Anderson & Elfert, 1989), even then, during those times the maternal role can also include functions other than caregiving.

Mothers Caregiving an Adult Offspring

In order to bring the literature review closer to the focus of this study (i.e., caregiving mothers of previously independent adult children), the literature dealing with maternal caregiving of adult children was searched. Howard's (1994) qualitative study was the only one found that dealt with maternal caregiving across the lifespan.

Howard (1994) described the experiences of mothers (n=10) who became primary caregivers to their adult children when they developed schizophrenia during their late adolescence or early adulthood (like Ryan's [1993] study). Howard examined maternal caregiving across the lifespan by focusing on the processes and problems of the caregiving role from the onset of the illness to the time the study took place. This end was accomplished by selecting participants' whose "care-years" varied (range = 1.5 to 28 years), allowing for various caregiving experiences to influence outcomes.

By using a grounded theory design to analyze participants' descriptions of their caregiving experiences, Howard (1994) formulated concepts and stages of maternal caregiving. Emphasis is placed on the processes that maternal caregivers go through in order to learn to live with children with schizophrenia. Towards this end, Howard found mothers go through four stages which are: (1) "Perceiving the Problem"; (2) "Searching for Solutions"; (3) "Enduring the Situation"; and (4) "Surviving the Experience" (p. 107).

Because maternal caregiving, as described by these mothers, is a "lifelong effort of trying to
help a chronically mentally ill child cope with life" (p. 112), these processes are constantly being influenced by overlapping and continuous "watching, working and waiting".

Howard pointed out that the processes and interactions are driven by the value that the mothers placed on their homes and families. This value is demonstrated by caring for family members. Howard concluded that the results of this study exemplifies the concrete ways mothers of adult children with schizophrenia value their child by providing lifelong maternal caregiving. This value motivated mothers to continue their caregiving with no expectations of being paid back for the giving of their services.

Although Howard's study is limited in that it looks only at those mothers who have sought out support from other mothers by joining the State Alliance for the Mentally Ill, it nevertheless gives a clear description of their experiences. Thus, this study adds another dimension to the caregiving role as it pertains to mothers who become primary caregivers to their adult children. That is, the caregiving is an ongoing, complicated process. However, because chronic schizophrenia is different than traumatic brain injury in that chronic schizophrenia is episodic in nature with unpredictable relapses and traumatic brain injury has a constant course, the findings of this study need to be viewed within that context.

Caregiving with an adult child with a TBI. In this section, the caregiving role, as it pertains to the mothers addressed in this study, is explored further. In doing so, literature that provides a further insight into the experiences of mothers who are caregiving their adult children with TBI is included.

Because Carson's (1992, 1993) qualitative study is focused exclusively on the caregiving of young adults who sustain TBI, it is included in this literature review even though it looks at the experiences of parents as a unit. Carson used grounded theory methodology to describe parents' experiences of caregiving 20 young adult offspring (aged 17
to 34 years: 50% aged 19-22) with "moderate-severe" TBI (p. 167). Parents were recruited through the National Head Injury Foundation as well as through health care facilities. Post injury time ranged from 8-70 months (mean = 31, SD = 4.58). All survivors had lived in the parental home following the injury albeit the length of time varied from 3-69 months (mean= 24.37, SD = 20.52). Prior to the injury, 55% (11) of the offspring with the TBI had lived independently. In 70% of the sample, the only child living with the parents was the child with the brain injury, the other siblings had left. Because Carson did comment on families that have only the male parent present, but did not give the number of those families, it is not clear as to how many mothers overall took part in the study. The interview format was mixed, that is, parents were interviewed together, and individually.

Carson's (1993) study resulted in identifying a process titled "Investing in the Comeback". It entailed the phases "Centering on; Fostering Independence; Seeking Stability" (p. 167). Carson underscored that the ultimate goal of the parents' caregiving role was to expedite "the child's achievements of optimal functioning" (p. 167).

In the "Centering On" phase, parents' "step in" to give the needed care, obtain needed services, provide a safe environment, and monitor the child's physical health (Carson, 1993, p. 167). At the same time, they are involved in "looking for the essential person" (p. 167). That is, those parents that believe that the pre-injury child is still in existence take actions to find the child by talking to the child, by looking for familiar mannerisms, and by providing a familiar environment, in hopes that the pre-injury child will emerge. However, for those parents whose child is so dramatically changed that they cannot believe "the pre-injury child's essence has survived", this part of the "Centering On" phase does not apply (p. 169).

In the "Fostering Independence" phase, parents' caregiving role shifts from doing activities for the child to supporting the child in doing their own activities by "exploring
possibilities" and "staying open" (Carson, 1993). When "exploring possibilities", parents' activities include: learning when and how to transfer self-care responsibilities back to the child; encouraging the child to participate in "normal" activities; encouraging and accepting decisions made by the child and "limiting rescue"; establishing and enforcing standards of behavior by using appropriate communication skills; and continuing to look for and become active in appropriate rehabilitation therapy and if not available, establishing "homebound rehabilitation" (eg. household chores) (p. 170). In the "staying open" activity, the caregiving role included groups of behaviors that are based on the parents remaining flexible about the child's "ultimate achievable skills" (p. 171). At first, because parents have looked for positive changes in the child since the injury, they disregard any negative changes that have occurred and continue to believe that the child will have a complete recovery and become independent. Thus, parents have a tendency to have a "personal trajectory" for the child's recovery (p. 171). Then, as time elapses, parents start expressing concerns about the possibility that some deficits might remain permanently and begin to moderate their expectations for a complete recovery although they continue to look for a 'good' recovery. Consequently, in order to reassure themselves that the child will regain complete independence, parents track the child's recovery behaviors. In doing so, parents start to differentiate the child's behaviors into those behaviors universal to all persons with brain injury and those that are uniquely the child's. Finally, parents take a stand about the severity of the deficits by such means as maintaining that the recovery is still in process, or by emphasizing all the positive opinions of others and ignoring negative ones (p. 172).

In the final phase, "Seeking Stability", the caregiving role consists of "incorporating" (Carson, 1993, p. 167). That is, parents establish a regimen that will maintain the optimal performance of the child with the brain injury, but, with minimal strain on the family. Thus,
parents come to realize that the child will not be able to resume independent living and start to plan for the child as being a "permanent part of the home setting" (p. 172). In doing so, parents continue to work towards maintaining the strides made by the child during the fostering independence phase.

Carson (1993) emphasized that moving through the phases is not linear nor is it based on time since injury. Parents can be drawn back to an earlier phase when there is any deterioration in the health of the child with TBI. Furthermore, mothers and fathers can experience the stages at different times.

Although in this study, Carson (1993) placed emphasis on the family system approach towards the caregiving of "survivors" with TBI (p. 17), the role of mothers is sometimes highlighted. For example, Carson notes three distinct variations of parental involvement with the offspring that included: (1) in the majority of families, mothers assumed the major responsibility for the caregiving role that included accomplishing tasks necessary for the child's rehabilitation; (2) in families who shared responsibility, the caregiving role was not formally divided but remained flexible; (3) and when only the male parent was present, the caregiving role was augmented by alternate caregivers earlier than in a two parent families.

Furthermore, Carson (1993) underscored that in the beginning "Centering On" phase, the process was not "collectively lived as a couple, but rather as an individual experience" (p. 169). However, the only experience elaborated on by Carson was the difference between how mothers and fathers "rescale priorities" in order to provide caregiving to the offspring with the brain injury. That is, in the beginning both parents rescaled their priorities, but, mothers and step-mothers maintained a rescaling of their priorities, while fathers revised theirs when they returned to work. Fathers were able to expand their activities and relationships beyond the child with the brain injury. In contrast, even those mothers who had
been employed outside the home prior to their children's head injury extended their leaves of absence and in some cases quit work altogether in order to provide caregiving tasks. In addition, Carson quoted specific concerns raised by mothers. These concerns included: how the mothers needed to monitor their children's health; and the difficulties they experienced when having to juggle appointments and transport their children to and from doctors and rehabilitation services.

Even though the majority of the mothers in this study took on the caregiving role, Carson (1993) maintained a focus on parents by reporting on their experiences as a unit. Therefore, although the three phase process described by Carson does facilitate the understanding of how parents view the experiences of living with a moderate-severe head-injured offspring, it can only be inferred as to how mothers view this experience.

In three other studies, specific aspects of TBI caregiving are described (Lezak, 1988; Solomon & Scherzer, 1991; Wilier, Allen et al., 1990). Lezak reported on findings based on observations gathered over several years of clinical practice with families who had members who had sustained a TBI. She noted that mothers as primary caregivers to their adult children with TBI were required to be constantly vigilant and had to intervene repeatedly in order to keep the child out of trouble. The inability of the child to generalize from past experiences resulted in the child always being at risk in new encounters.

In Wilier, Allen et al.'s (1990) Canadian study, finding appropriate services was a caregiving activity reported by mothers (n=13) of young sons (aged 14-25 yrs.). The sons had sustained TBI at least 18 months previously and lived with their mothers. And, in Solomon and Sherzer's (1991) interviews with families (n=over 100), it was mothers who were found to be the primary caregivers and in charge of their child's rehabilitation. This activity included either taking on the case management role when the child was discharged
from hospital, or becoming primary therapists when health professionals refused to work with the child because their behaviors were interpreted as being non-compliant or disrespectful. In this regard, because the mothers persevered, the child's functioning frequently improved. As a result, in most situations, the child would shirk any further interventions by the mother long before they were competent to operate independently. At those times, poor judgement and poor decisions created havoc, and the mothers waited and prepared to intervene if their help would be accepted.

In summary, this part of the literature review focused on maternal caregiving of adult children, and in particular maternal caregiving of adult children with TBI. Thus, the existing knowledge of maternal caregiving of adult children, especially those with TBI, was explored.

**Burden within Caregiving**

In this section, the caregiver burden literature is reviewed in order to determine what the effects of caregiving an adult child with TBI will have on mothers. Caregiver burden is delineated as the impact of caregiving on the caregiver as a result of providing care to the care recipient (Alley, 1988). The term caregiver burden was first coined by Grad and Sainsbury (1968) in their early research on family caregiving of their mentally ill family member. Since then, much research has been conducted that has attempted to define and conceptualize caregiver burden as it relates to the caregiving of the elderly (Deimling & Bass, 1986).

Based on Grad and Sainsbury's (1968) categorization of burden into "external burden" that addressed the actual physical care and "internal burden" that included thoughts and attitudes about the situation (p. 265), Montgomery, Gonyea and Hooyman (1985) proposed that the burden experienced by caregivers to the elderly fell into two categories, "objective burden" and "subjective burden" respectively. Montgomery et al. expanded the categories of
burden so that objective burden took into account the "extent of disruptions or changes in
various aspects of the caregiver's life and household", and subjective burden addressed the
attitudes towards and reactions to the caregiving experience (p. 21).

Montgomery et al. (1985) operationally defined objective and subjective burden. Objective burden addressed the amount of change that the caregiver had experienced in nine areas of his or her life since beginning the caregiving and included: the amount of time for oneself, personal freedom, time for social or recreational activities and vacations, privacy, money, energy, and changes in the caregiver's health and relationships with other family members (Alley, 1988). Subjective burden dealt with the negative and positive feelings experienced by the caregiver that were related to both the caregiving and to the care recipient while providing care. Negative feelings could include: "feeling pain at watching the relative age"; fear about what the future holds; problems in the relationship with the care recipient; guilt about not doing as much for the care recipient as could or should be done, and negative reactions to the care recipient that resulted from how the care recipient treated the caregiver (Alley, p. 10). Positive emotional responses encompassed the useful feelings resulting from being able to contribute to the well being of the care recipient and the pleasurable feelings associated with the good relationship with the care recipient. The categories under objective and subjective burden serve as a guide for the following overview of caregiver burden.

In keeping with the previous section on the caregiver role, the bulk of caregiver burden literature reviewed in this section deals with female caregivers providing care to elderly persons with Alzheimer's disease or dementia. Caregiver burden literature associated with both male and female caregivers providing care to the frail elderly is also included.

**Impact on relationship.** The first item of caregiver burden to be addressed is changes in family relationships and problems in the relationship with the care recipient. Most
research findings have revealed that cognitive impairment in the care recipient does not contribute to caregiver burden (Fitting, Rabins, Lucas & Eastham, 1986; George & Gwyther, 1986; Zarit, Reever & Bach-Petersen, 1980). However, caregiver burden is experienced when the care recipient's disruptive behavior and impaired social functioning caused by the progression of Alzheimer's disease is taken into consideration (Deimling & Bass, 1986). These changes in the care recipient have a negative impact on the relationship between the caregiver and care recipient (Deimling & Bass; Johnson & Catalano, 1983; Poulshock & Deimling, 1984; Rabins, Fitting, Eastham & Fetting, 1990). Frequently, caregivers become the targets of the care recipient's aggressive behavior caused by their becoming frightened and frustrated when their deteriorating condition makes them feel bitter and humiliated (Cutler, 1985). Conflicts arise between the caregiver and care recipient when the care recipient's manifestations of mood deterioration precipitate the decline of social supports (Deimling & Bass; Johnson & Catalano).

Furthermore, the normal adult to adult relationship that includes the bidirectional exchange of valued resources between individuals, called reciprocity (Tilden & Gaylen, 1987), is not forthcoming from cognitively impaired or disoriented persons (Deimling & Bass, 1986; Lindgren, 1993). Cognitive impairments limit the care recipient's ability to give feedback in response to the care they receive (Deimling & Bass).

**Social isolation.** In the literature, the ubiquitous theme of caregiver burden is social isolation (Abel, 1989; Bowers, 1987; Brody, 1985; Cantor, 1983; Chenoweth & Spencer, 1986; Deimling & Bass, 1986; Fengler & Goodrich, 1979; George & Gwyther, 1986; Hoyert & Seltzer, 1992; Lindgren, 1993; Zarit, Todd & Zarit, 1986). The care recipients' behaviors have been attributed to causing social isolation (Deimling & Bass), especially when family and friends stop visiting because of those behaviors (Fengler & Goodrich). In addition,
maintaining social contacts and activities can be thwarted by the caregiving demands (Abel; Cantor; George & Gwyther; Hoyert & Seltzer) and by not being able to get away from home (Abel; Brody; Chenoweth & Spencer; Montgomery et al., 1985).

**Time commitment.** The time required to provide caregiving is identified as a major caregiver burden (Archbold, 1983; Cantor, 1983; Hoyert & Seltzer, 1992; Stuave & O'Donnell, 1989). Time constraints can: prohibit the maintaining of social contacts, and thus contribute to social isolation (Cantor); serve to thwart activities such as vacations and hobbies (Cantor); and infringe on the caregiver's employment (Archbold; Hoyert & Seltzer; Stuave & O'Donnell). If employment is sustained then role overload can occur because of lack of time (Stuave & O'Donnell). Furthermore, the longer the duration of caregiving the more negative the outcomes (George & Gwyther, 1986; Hoyert & Seltzer).

**Impact on privacy.** Living within the same household as the care recipient is associated with greater burden being experienced by the caregiver (George & Gwyther, 1986; Horowitz, 1985; Hoyert & Seltzer, 1992; Zarit et al., 1980). The presence of the care recipient in the home interrupts privacy for the caregiver (Archbold, 1983).

**Impact on energy.** Another facet of caregiver burden is the physical demands of caregiving (Brody, 1985; Rabins, Mace & Lucas, 1982) that can result in caregivers experiencing exhaustion (Chenoweth & Spencer, 1986; Crossman, London & Barry, 1981; Rabins et al.). Caregiver exhaustion can also arise from interrupted sleep and chronic sleep deprivation caused by caregiving demands (Lindgren, 1993). Although hands-on caregiving tasks have been considered to be the most demanding (Archbold, 1983; Montgomery et al. 1985), it is reported that the constant vigilance that is required because of the care recipient's behaviors contributes to caregiver burden as well (Barnes, Raskind, Scott & Murphy, 1981; Chenoweth & Spencer). Attempts have been made to identify which aspects of the role are
more demanding and opinions that are offered differ from one another. In the past, researchers have maintained that providing hands-on tasks is more burdensome (Archbold), however, recent research findings have underscored that there is a similarity between the amount of caregiver burden experienced by caregivers who give direct hands-on care and those who provide "supervisory care" (Pohl, Boyd, Liang & Given, 1995).

Financial burden. Although financial burdens are associated with the caregiver role (Cantor, 1983; Crossman et al., 1981; Fengler & Goodrich, 1979; George & Gwyther, 1986), it is not universal to all caregivers and is dependent upon the resources available to them (Archbold, 1983). That is, caregivers' socio-economic bracket influences the degree of burden experienced, with those in higher income brackets being able to purchase services that substitute for the tasks required by the role (Archbold). Whereas, in some situations, caregivers can experience increased financial burden that will limit any social participation requiring financing (Fengler & Goodrich; George & Gwyther).

Impact on personal freedom. Caregivers can experience loss of personal freedom to attend to their own needs (Archbold, 1983). As well, disruption in the caregiver's daily life often occurs when the caregiver role is assumed (Brody, Hoffman, Kleban & Schoonover, 1989; Robinson & Thurber, 1979) with role overload frequently occurring (Brody, Kelban, Johnson, Hoffman & Schoonover, 1987; Skaff & Pearlin, 1992). The caregiving role is demanding and competes with other roles held by caregivers often resulting in their giving up outside activities, jobs, volunteer work, and leisure activities (Abel, 1989; Chenoweth & Spencer, 1986). Consequently, the overall lifestyle of the caregiver can be affected (Brody et al., 1987; Robinson & Thurber) and this can have a negative impact the caregivers' feelings of life satisfaction (Fengler & Goodrich, 1979; George & Gwyther, 1986).
Subjective burden. Within the area of negative subjective burden, feelings of loss are experienced when irreversible deterioration occurs in the family member resulting in losses of the communication patterns and changes to the former personality (Abel, 1989; Kapust, 1982; Lindgren, 1993). In addition, feeling worried about the future (Marcus & Jaeger, 1982) and feeling irritated with the "daily" caregiving role are reported (Archbold, 1983). Within the area of positive subjective burden, families reported that the caregiving experience drew them closer together (Chenoweth & Spencer, 1986). They also reported that they found the experience gratifying (Abel).

The degree of burden experienced by caregivers is influenced by factors such as the caregiver's general health status (Pratt, Wright & Schmall, 1987), and the resources available (George & Gwyther, 1986; Kapust, 1982). The relationship between the caregiver and care recipient, that is, whether the caregiver is a spouse or daughter, is found to influence the degree of caregiver burden as well (Hoyert & Seltzer, 1992; Zarit et al., 1980). Hoyert and Seltzer reported that caregiving based on intergenerational relationships was less burdensome than that based on intragenerational relationships.

In summary, caregiver burden is associated with the impact that negative changes to the behaviors of care recipients have on the relationship between the caregiver and care recipient. Caregiver burden is also related to social isolation, time infringements, living with the care recipient, physical and financial demands, demands related to caregiving vigilance, loss of freedom, disruption in lifestyle, role conflict, and decreased privacy. Dealing with the losses to the care recipient's personality, worrying about the future, and feeling irritated with caregiving demands, also adds to caregiver burden. Caregiving can be a positive experience. The caregivers' health status, resources and familial relationship with the care
recipient influence the degree of caregiver burden. Caregiver burden will differ according to the needs of the care recipients.

The concept of caregiver burden has "emerged as a unifying notion which was shared by diverse caregivers to diverse populations" (Kahana & Young, 1990, p. 76). Recently, it is found that there is a lack of empirical research to back up the taking of a "unidimensional view" about caregiver burden (p. 76). For example, in Perry's (1996) grounded theory qualitative study of women caregiving husbands who had Alzheimer's disease, she found that burden did not emerge either as a theme or a sub theme in the data. She noted that burden was simply not the caregiver's organizing theme, instead, the wives organizing theme was "caring" even though the caregiving could be extensive and over long periods of time. Thus, Perry's findings are in contrast to the prevailing research presented in this literature review. Accordingly, caregiver burden cannot be considered a unidimensional activity (Deimling & Bass, 1986; Poulshock & Deimling, 1984), but has to be considered within the context of the caregiving situation. Therefore, the caregiver burden literature reviewed thus far, that is, caregiving of the elderly with dementia or Alzheimer's disease, can only be viewed as a guide as to the caregiver burden experienced by caregiving mothers of adult children with TBI. To bring this literature review closer to what this study addresses, literature pertaining to caregiver burden experienced by mothers caregiving their adult children is presented in the following section.

**Caregiving Mothers and Burden**

In order to describe caregiver burden as it relates to mothers caregiving adult children, this segment of the literature review will focus on research reports that address caregiver burden associated with mothers caregiving adult children with cognitive and/or mental disabilities. By focusing on these mothers, one aspect of the context in which the caregiving
has taken place is consistent with the previous section of this literature review, that is
caregiving adult care recipients with cognitive and/or mental disabilities. The caregiver
burden research selected addressed caregiving mothers of Down’s syndrome children
(Damrosh & Perry, 1989), and chronically disabled children with cerebral palsy and mental
retardation (Waddington & Busch-Rossnagel, 1992). Both conditions had been present since
birth. In addition, caregiver burden studies of mothers of adult children who had developed
schizophrenia are included (Belcher, 1988; Wheeler, 1994): As stated previously, the
manifestation of this condition generally occurs in the child’s late teens or early adulthood.
These studies were reviewed for objective and subjective burden.

In these studies, several categories of objective and subjective burden are identified
which are similar to the findings of the caregiver burden literature related to caregiving the
elderly. That is, as a result of the demands of routine caregiving tasks, caregiving impacted
on the mothers’ time and energy (Waddington & Busch-Rossnagel, 1992), caused physical
exhaustion (Wheeler, 1994), and affected mothers’ sense of physical well-being (Damrosh &
Perry, 1989; Waddington & Busch-Rossnagel). Also, social isolation was a predominant
theme caused by loss of personal freedom related to the caregiving demands (Belcher, 1988;
Waddington & Busch-Rossnagel, 1992). As well, the inappropriate behaviors manifested by
the child made people stop visiting and meant that mothers had to continually watch over
them in order to prevent any untoward happenings (Belcher). As a result, mothers
experienced disruption in their social lives and restrictions on outside activities such as
vacations and holidays (Wheeler). Financial burdens are noted and are situation dependent
(Belcher). That is, if the mothers had sufficient financial resources and/or if the child was
able to hold a paying job then financial burden was not experienced (Belcher). Also, a
positive relationship was found between the length of time that caregiving was provided and
caregiver burden, that is, as the length of time increased, then the overall caregiver burden increased (Belcher). Furthermore, mothers whose children had developed schizophrenia described feelings of loss related to the changes in personality and behavior (Wheeler).

Several areas of objective and subjective caregiver burden are noted that are unlike the caregiver burden literature of the elderly. These areas are highlighted as follows. First, social isolation was found to be attributed to stigma (Belcher, 1988; Wheeler, 1994), as well as the child's reluctance to go out of the home (Belcher). In some cases, mothers were found to be embarrassed and self conscious to be seen in public with their child (Damrosh & Perry, 1989). Also, in Damrosh and Perry's study, almost all of the mothers experienced chronic sorrow. Chronic sorrow is defined as the "periodic re-evocation of intense feelings of grief throughout the life span of the handicapped child" (p. 25). Moreover, these mothers experienced worry (Belcher) and fear (Belcher; Damrosh & Perry; Wheeler) that embraced: feeling fearful (Damrosh & Perry) and worried (Belcher) about the future in general (for themselves and the overall situation); having a specific "fear" and uncertainty about the child's well-being and future (Wheeler); feeling fearful about what people were saying about them (Damrosh & Perry); and living in fear of their children (Belcher). Furthermore, mothers described feeling jealous about others who had children who were "non-handicapped" and feeling guarded about their child being handicapped (Damrosh & Perry). In addition, mothers related being preoccupied about the child's problems (Wheeler).

Along with the negative subjective, researchers have found that these mothers experienced positive subjective burdens (Belcher, 1988; Damrosh & Perry, 1989). That is, mothers reported feeling grateful for the good things about the child (Damrosh & Perry). Furthermore, those mothers who were required to provide only temporary caregiving related feeling good about being able to help their child (Belcher).
Caregiver Burden in Mothers of Adult Children with TBI

In this segment, literature that addresses caregiver burden specific to mothers caregiving adult children who have sustained TBI is explored. In doing so, the literature is presented under specific categories of caregiver burden.

Impact of changes to former personality. Nurse researchers', Mauss-Clum and Ryan (1981), ground-breaking pilot study described the experiences of 11 mothers and 19 wives of male veterans with a sudden brain injury. These individuals were connected to a Brain Injury Unit (BIRU) specific for veterans. The diagnosis of the veterans varied and included TBI (n=17), vascular accidents (n=9), and diseases such as Alzheimer's or Parkinson's (n=4). The sample was comprised of: (a) approximately 50% aged 20-35 years who had been involved in a traumatic accident; and (b) the remainder aged 50-65 years who had suffered a stroke or cardiac disease. Because this study is frequently referred to by researchers of TBI, it is included in this literature review.

Mauss-Clum and Ryan (1981) reported on participants' responses to a questionnaire developed from their impressions gleaned during their clinical practice in the BIRU. In the findings, 90% of the wives and mothers found changes to the client's personality caused the most difficult adjustment problems, particularly, decreased memory and dependency, whereas "reduced intelligence" was considered not as difficult (p. 167). All of the mothers reported that they experienced frustration with the situation, and over half reported experiencing irritability and annoyance, with only nine percent experiencing fulfilment. None of the mothers felt criticism about the care that they gave to their children. However, caution is needed when interpreting the mothers' reactions. It is not clear whether the mothers are caring only for those clients that have TBI or those clients that have brain diseases or vascular
accidents. Furthermore, because of the small sample size and variability of age, caution has to be taken about generalizing the findings of this study.

In longitudinal studies conducted by Glasgow research groups of Livingston et al. (1985a, 1985b) and Brooks et al. (1986, 1987), primary family caregivers of persons with severe head injuries were followed over the course of seven years. These studies sought to determine their sense of burden related to the post traumatic changes to the family member’s personality and behavior. The overall attrition rate of original sample (n=55) was 24%. Caregivers either lived with or had personal daily contact with the person with the head injury. The researchers used semi-structured interviews and a structured questionnaire, developed by the group and based on the work of Grad and Sainsbury (1968), to measure the caregivers' subjective and objective burden. Thus, only those changes to the member's personality and behavior as reported by family caregivers were classified as objective burden. The subjective burden addressed only the negative effects of the objective burden on the caregiver and was measured on a seven point scale.

Data were obtained at three and six months and one, five and seven years. Although initially personality and behavior changes were not reported by all the caregivers, at the one year mark all reported that their family member had undergone behavioral, personality and cognitive change. At all points in the data collection, a positive relationship was reported between the number of personality and behavior changes (as rated by the caregiver) and subjective burden being experienced by the caregiver. However, the degree of subjective burden experienced was not related to the number of changes in the person with the head injury. Consequently, the researchers concluded that factors not identified in the research tools had an effect on the degree of caregiver burden experienced.
Personality changes that impacted most on caregivers were irritability, anger, mood swings, decreased energy and lack of enthusiasm. Memory problems, repeating questions and losing track of things was found to be distressing by the caregivers. In addition, at the five year mark, violence had risen with 47% of the care recipients threatening violence and 26% of the care recipients actually carrying it out. Overall moderate or high subjective burden was found at both the fifth and seventh years, with 83% of the caregivers relating the subjective burden to violence, aggressiveness, childishness and dependency manifested by the person with the TBI. Changes to personality did not reduce over the span of seven years and in some cases increased. In many cases, caregivers reported an increase in subjective burden. Although the sample included spouses, parents, other relatives and friends, a detailed analysis found no relationship between the burden and the relative's status, with the exception that mothers showed higher levels of burden.

In Lezak's (1986, 1988) writings, impulsivity, acting out, impaired control, restlessness, agitation, repetitive behaviours as well as memory problems are reported as creating disruption and burden in the mothers' lives. But, in addition to the problematic personality and behavioral changes, Lezak (1986) found that persons with TBI often did not respond to their own needs or to their environments and this added to the caregiver burden. She emphasized that it was not a case of the person with the TBI knowing what they could do as much as how and whether they would or could respond and do it. As a result, because of their inability to "adapt what they know to everyday circumstances", they often were unable to carry out what they could do independently (1986, p. 246). Mothers, as caregivers, were required to intervene and assist their adult children with TBI.

Rees' (1988) anecdotal report stressed that the burden on mothers with adult children with TBI was more severe if the child appeared to have made a good recovery but in fact did
have deficits of memory, behavior, and coordination. In those cases, the children looked normal but often were aggressive, and the mothers experienced frustration when they were not believed when describing the child as aggressive. Also, even if the child was able to live in the community, the memory lapses precluded them from holding jobs and caused their relationships to suffer.

A previously described study by Willer, Allen et al. (1990) reported that mothers experienced burden related to their sons' behavior, such as mood swings. In addition, the mothers found their sons' planning deficiencies and inability to manage money "in an age appropriate manner" burdensome (p. 170).

Another previously described study by Solomon and Scherzer (1991) noted that mothers often became victims of their own success when the offspring with the TBI became more independent but not competent to live independently. Not only was the mother's help rejected, but the offspring with the TBI often concluded that the mothers were striving to keep the offspring dependent on the mothers and would verbally abuse and sometimes physically abuse the mothers. At those times, the mothers had to stand back, watch and experience powerlessness.

In Kinsella, Packer and Oliver's (1991) quantitative study, forty mothers of sons, aged between 17-35 years (mean=27 years), who had sustained a "very severe closed head injury" took part along with a control group of forty mothers of sons matched by age and education and no premorbid history was sought about the TBI (p. 422). The sons in both groups either lived with their mothers or had frequent contact with them. Chronicity of the head injury was established by the sample being two to 15 years post-injury with 68% of the sample being five years or longer post-injury. A stepwise Discriminant Function Analysis was undertaken. Like the previous studies, the findings revealed that loss of emotional control in
the sons was related to the emotional distress in the mothers with disinhibition, impulsivity, frequent mood changes such as short temperedness, quarrelsomeness, restlessness, and self-centredness being the behaviors most frequently reported. In this study, lack of motivation was not found to be related to the mothers' emotional distress, nevertheless the mothers did report their sons' lack of initiative and energy to be a problem. No co-relationship was found between chronicity and the mothers reporting of the behaviors, and the behaviors manifested by the sons with TBI were found to be chronic, which supports the findings of the Glasgow group.

**Changes to physical functioning.** Although changes to physical functioning are present following TBI, participants in Mauss-Clum and Ryan's (1981) study reported that physical disability was not considered to be a problem when compared to behavior changes. Furthermore, the Glasgow group found that caregivers did not experience subjective burden related to the physical changes in the family member (Brooks et al. 1986, 1987; Livingston et al., 1985b). Moreover, Rees (1988) reported that mothers whose children with TBI who were obviously affected with physical disabilities, but not with intelligence deficits, were often sad and compared their situations to the "walking wounded", but they often had less burden (p. 74).

**Social isolation.** Following their adult child's TBI, researchers have found mothers experience a decline in their social functioning (Brooks et al., 1986, 1987; Livingston et al., 1985b) and social isolation (Carson, 1992, 1993; Kozloff, 1987). In Kozloff's qualitative study, the structure, content, and function of social networks of 37 adults with severe head injuries and 39 of their significant others, which included 18 mothers, were determined. The researcher's used anthropological procedures that consisted of participant observations, interview guides, unstructured interviews and network analysis. Kozloff found that the
network sizes of persons with the TBI decreased as "postinjury" time increased and was attributed to their inappropriate behaviors. Past relationships ended because the behaviors were too demanding, and new relationships were either transitory in nature with no commitment involved or opportunistic wherein advantages were taken against the survivor. For the unmarried people with TBI who lived at home, families compensated for the loss of relationships and social interactions by spending more time with the survivor. As a result, these families frequently became socially isolated because of the increased demand on their time and energy. Family members, other than mothers, stopped providing support when they tired of role changes brought about by the presence of the survivor. In these situations, Kozloff found that mothers were the only source of task-oriented, social and emotional support for their child with TBI. Furthermore, mothers gave up friendships and socialization to provide care for the offspring with the TBI. Kozloff emphasized that the relationship between the single patient and his or her mother was found to be the "most resilient" (p. 23).

Similarly, in Carson's (1992, 1993) study, all parents reported changes in the child's peer relationships, with a near total loss of friends experienced by most children with TBI resulting in social isolation being a problem for the child. However, the degree to which mothers compensated for this loss is not discussed. Families experienced social isolation when they focused exclusively on the child during the first phase of caregiving. Additionally, many parents continued feeling isolated because they felt they were living a "totally unique experience" (1993, p. 173).

In Kinsella et al.'s (1991) research, based on the Self Report Social Adjustment Scale, contradictory findings are noted. That is, mothers of the head-injured were performing as well as the control group in social and leisure functions and no differences were found between the social adjustment of the mothers of sons with TBI and the control group. The
mothers had managed to get on with their lives and had accommodated to the "intrusion of the TBI" (p. 425). However, the researchers emphasized that the mother/son relationships in this study had survived the head injury, and might not be representative of all mothers whose sons have sustained a TBI. Furthermore, no distinction was made between those mothers whose sons lived with them or apart.

**Time.** In the literature, the time factor comes under two major classifications. The first included the impact of time spent caregiving, and the second took into account what happens over time. In the first category, Kozloff (1987) found that increased caregiving took time away from socialization. Carson (1993) noted that parents reported a "self-imposed embargo" on spending time or energy on "foci extraneous to the brain-injured child" (p. 168). In addition, Carson found that initially and in later stages parents reported that the time required to provide caregiving was all encompassing, although, time needed for performing physical care lessened when the caregivers became more skilled (Carson, 1993).

In the second category, burden was associated with changes over time to the interpersonal relationship between the mothers and their children with the TBI. Specifically, Kinsella et al. (1991) found that the interpersonal relationships between the sons and the mothers had substantially changed since the time of the injury and was related to the behavioral and personality changes in the sons. The Glasgow group identified that mothers' toleration of the behavioral changes in their child, as well as the mothers' ability to accept or manage the changes that for the most part were negative, decreased over time (Brooks et al., 1986, 1987; Livingston et al., 1985b). This factor accounted for the increased association between the personality change and burden in their studies.

**Couple relationship.** Frequently, TBI in an adult child was found to have a negative impact on the marriages of mothers who were providing primary caregiving (Carson, 1993;
Kinsella et al., 1991; Lezak, 1988; Willer, Allen et al., 1990). Kinsella et al. reported that these mothers' relationships with their spouses suffered. Carson and Lezak emphasized that prior to the TBI many couples were in the final stage of raising their children and had more free time to cultivate their couple relationship and make retirement plans. These activities halted with the returning of the "new" child to the family home (Carson). Furthermore, family discord often happened from having the child with the TBI in residence and frequently the discord resulted in marriage breakdown and sometimes divorce (Lezak, 1988; Willer, Allen et al., 1990).

Financial impact. In Carson's (1993) study, all parents reported economic alterations and employment changes that included terminating employment, leaves of absences, rescheduling and reducing work hours. Carson, Kinsella et al. (1991) and Kozloff (1987) noted that it was the mother's work role that was affected most. And, when these mothers gave up their jobs, the household social standing decreased (Kozloff). Furthermore, Lezak (1988) reported that when previously financially independent adult children who sustained TBI became unemployable and had no other sources of funding, families were required to provide the financial assistance, as a result, not only did mothers suffer financially, but, families as a whole suffered. Willer, Allen et al. (1990) found extra financial burden was often reported by families who were required to remodel or relocate homes in order to accommodate the survivors with physical limitations. Nevertheless, in Mauss-Clum and Ryan's (1981) findings, financial problems were not considered to be as difficult a problem as behavior or personality changes in the adult who sustained the TBI.

Physical impact. In Carson's (1993) study, all parents described that they experienced a "constant drain of energy" during the early stages of caregiving (p. 169). At later stages of caregiving, Kozloff (1987) noted that mothers also experienced a drain on energy.
Fears. Being fearful about the child's future (Carson, 1993; Lezak, 1988; Mauss-Clum & Ryan, 1981), as well as being fearful about the child's behavior (Brooks et al., 1986, 1987) is reported. In regards to the child's future, because these mothers are committed to a lifetime of caregiving they are concerned about what will happen to their child with the TBI in the event of "their serious illness or death" (Mauss-Clum & Ryan, 1981, p. 168). Being fearful about the child's behavior was reported by caregivers whose care recipients manifested aggressive behavior (Brooks et al.; Livingston et al., 1985b). Because of the aggressive behaviors, caregivers reported having to communicate cautiously and being unable to leave the person with the TBI alone because of what they would do (Brooks et al.).

Feelings of loss. Feelings of loss associated with changes to the former personality of the child was reported (Brooks et al., 1986, 1987; Livingston et al., 1985b). In addition, Kinsella et al. (1991) noted that feelings of sadness and sorrow in the mothers emerged early and did not get resolved over time.

Impact of lack of services. A lack of services is a prevalent theme found in international as well as Canadian literature (Mauss-Clum & Ryan, 1981; Rees, 1988; Willer, Allen et al., 1990). For example, in 1981, Mauss-Clum and Ryan's American study found that because of the lack of facilities, both respite and long-term, mothers' concerns about the future for their children were increased. In 1990, all mothers in Willer, Allen et al.'s Canadian study reported having difficulties in finding services. Most often, the sons did not qualify for existing services. These findings are reinforced in Rees' anecdotal report based on the British experience. That is, Rees emphasized that the system is geared towards those that are affected physically, thus, those parents have a better time finding services and are not as burdened.
In this section, the literature reviewed addressed caregiver burden associated with females caregiving their cognitively impaired elderly family members, and mothers caregiving their adult children with cognitive/mental disabilities, and in particular mothers caregiving adult children with TBI. By focusing the review in this way, the impact that caregiving an adult child with TBI has on mothers is placed within the current knowledge of caregiver burden.

**Caregiver’s Management of Burden**

In this part of the literature review, how caregiving mothers of adult children with TBI manage their caregiver burden will be presented. Towards this end, caregivers of the elderly ways of managing situational burden is first discussed. This section will be followed by a review of caregiving mothers of adult children attempts to manage caregiver burden. Then, the literature addressing the specific management efforts used by mothers of adult children with TBI will be examined.

**Caregivers of the Elderly Attempts to Manage Situational Burden**

In this section of the review, only findings from qualitative nursing and behavioral science research that focused on caregivers of the elderly ways of managing caregiver burden are reviewed. In this context, managing situational burden refers to the cognitive and behavioral efforts by caregivers to master, reduce, or tolerate the objective and subjective burden created by the caregiver role (Chwalisz, 1992). The findings are presented under the two categories; cognitive and behavioral efforts.

**Cognitive efforts.** First, caregivers' used strategies to manage changes to their relationship with the care recipient caused by alterations in the care recipient's behavior. Caregivers' strategies included: reminiscing about the past relationship and going over times and events shared with the care recipient (Langner, 1993; Neufeld & Harrison, 1995);
wanting to return the help given by the care recipient (Neufeld & Harrison); and managing difficult times by "retelling" themselves why they became caregivers (Langner, p. 590).

In addition, caregivers constructed strategies to make up for lack of reciprocity in the relationship caused by the care recipient's disorientation (Neufeld & Harrison, 1995). These strategies entailed: (1) reducing expectations for clear responses; (2) monitoring and observing care recipient's reactions and reading into behaviors and interpreting indistinct and subtle cues as positive feedback; (3) waiting for "good days" when care recipients recognize the caregiver or can recall past shared experiences; and (4) placing a value on the commitment to care give, therefore, being able to give into the relationship without expecting any return (p. 356).

Cognitive strategies were also used by caregivers to manage overall caregiver burden. Osterkamp ([1989], as cited in Cameron, 1994) reported that caregivers use "reframing" by comparing their situations to hypothetical situations that are more difficult, and by taking the care recipient's perspective. In addition, caregivers use the management strategies of taking it "one day at a time" (Langner, 1993; Lindgren, 1993), and accepting the present situation and uncertain future (Langner).

**Behavioral efforts.** Several caregiver behavioral strategies were found that include:

1. Getting information about what is happening to the care recipient (Abel, 1989; Lindgren, 1993), so that caregivers could take charge of the situation and problem solve in ways that have meaning for them, thus, solutions are not imposed on them by others (Lindgren).

2. Establishing and maintaining a routine (Archbold, 1983; King, 1993; Langner, 1993), and especially one that works for the care recipient (Archbold), as well as for themselves (King).
3. Findings ways to reduce the physical demands of hands-on caregiving tasks (Lindgren, 1993) by: seeking assistance with tangible chores (Abel, 1989); purchasing services if financially able (Archbold); and seeking respite care (although this strategy is only a temporary solution for managing caregiver burden [Richey & Hodges, 1992]).

4. Redefining the caregiving relationship by: establishing physical and emotional distance to manage the day to day caregiving demands (Johnson & Catalano, 1983; King, 1993); including others to help with the caregiving (King); or becoming enmeshed in the life of the care recipient and entrenched in the caregiving role to the exclusion of others (Johnson & Catalano).

5. Setting limits with the care recipient by: altering communication patterns by reducing the time taken to converse with the care recipient; using self-talk that includes giving themselves permission to give the problem back to the care recipient; suggesting to the care recipient other ways to get their needs met; avoiding taking on tasks; being realistic about the amount of help they can provide; and taking charge of their own emotional reactions and not feeling responsible for the care recipient (King, 1993).

6. Seeking out support by using various strategies (Abel, 1989; Lindgren, 1993) that include: (1) looking for support from professionals (Morton & Mackenzie, 1994); (2) getting support from family or friends (Chenoweth & Spencer, 1986; Zarit et al., 1980); (3) seeking out supportive friends for advice and information and for socialization (Lindgren); (4) confiding in confidantes either daily or weekly (Fittings et al., 1986). In contrast, some caregivers find that looking for support from family or friends can be stressful (Abel; Lindgren) and, in doing so, find their own needs can be submerged (Abel).

7. Joining support groups (Abel, 1989; Morton & Mackenzie, 1994). Caregivers use support groups because: (1) mutual support, respect and caring is received from people who
understand their situations and thus social isolation is reduced when they know they are not alone (Morton & Mackenzie); (2) a milieu is provided in which situations can be compared with others with more problems thus situations regarding care recipient’s behavior can be reinterpreted based on the experience of others (Abel); (3) information from professionals (Morton & Mackenzie) and others in similar situations (Abel) can be obtained. Support groups are also places where caregivers can: discuss problems, unburden (Morton & Mackenzie) and to get advice about making decisions such as making plans for the future; get ideas for placing appropriate limits on their obligations (including ignoring unreasonable requests for help, and readjusting expectations on themselves so that they take on only what is reasonable) (Abel); and get ideas about actions for lobbying for change (Morton & Mackenzie). However, not all caregivers find attending support groups beneficial, and caregivers withdraw from social situations that are not helpful (Abel).

8. Turning to religion and prayer (Whitlatch, Meddaugh and Langhout, 1992). Some organized religions provide: formal help such as respite services and adult day care; informal support such as emotional support and information; and social activities for caregivers. Praying is used by caregivers to get a sense of hope and meaning to their lives and situations. Praying can be grounded within the caregiver’s religion or their intrinsic spirituality or through attendance at religious activities (Whitlatch et al.).

9. Institutionalizing the care recipient when caregiver burden becomes insurmountable (Lindgren, 1993). Most often institutionalizing is used only as a last resort because caregivers are tenacious in their role, therefore, convincing from families and physicians is frequently required (Chenoweth & Spencer 1986; Lindgren).

In summary, various strategies are used by caregivers to manage their caregiver burden resulting from providing informal caregiving to the elderly. Not all strategies are
useful to all caregivers. Thinking about the past relationship held and experiences shared prior to the onset of needing caregiving helped the caregiver to manage the caregiving role. Strategies to manage the lack of reciprocity in the adult to adult relationship are developed and used. Caregivers use their thought processes and purposefully change their thinking to help manage their caregiver burden. They take actions to limit the impact of the hands-on caregiving tasks and to gain control of the caregiving situation. Caregivers use support from family, friends, professionals and support groups. Caregivers take a one day at a time attitude. Socioeconomic background, the disabilities of the care recipient, and the dynamic individual situations influence the kind of caregiver burden management strategies that are used.

Caregiving Mothers' Management of Burden

In order to bring caregivers' attempts to manage caregiver burden into the realm of the mothering role, this section of the literature review is focused on mothers' attempts to manage caregiver burden. To do so, findings from both qualitative and quantitative studies that addressed mothers who are caregiving adult children with cognitive/mental disabilities are highlighted (Belcher, 1988; Cameron et al., 1991; Howard, 1994; Ryan, 1993; Wheeler, 1994). Like the caregiving and caregiver burden section, the majority of studies found looked at mothers of adult children with schizophrenia (Belcher; Howard; Ryan; Wheeler), and one exception looked at mothers of adult children with delayed development (Cameron et al.). Although some strategies used by these mothers are similar to the management strategies used by caregivers of the elderly, strategies specific to mothers' caregiving their adult children were also identified.

Strategies similar to those used by caregivers of the elderly included: having faith in the Lord (Belcher, 1988); going from day to day (Ryan, 1993); using "reframing" by
redefining problems to make them more manageable (Cameron et al., 1991); and seeking support (Howard, 1994; Ryan; Wheeler, 1994) and knowledge (Howard). Furthermore, the dynamics of why mothers seek out support parallels those of the caregivers of the elderly. That is, only those work colleagues who understood and accepted the illness were approached for support (Wheeler). In addition, by attending support groups, mothers were able to freely share their feelings (Ryan), and get knowledge pertinent to their caregiving situations (Howard).

Strategies used by mothers, that are different from those used by caregivers of the elderly, included an emphasis on hope. Mothers identified having and maintaining hope as being a paramount strategy for coping with their situations (Belcher, 1988; Ryan, 1993; Wheeler, 1994). This strategy included hoping things would work out (Belcher) and focusing on keeping their beliefs (Wheeler) and hope strong (Ryan; Wheeler). Furthermore, one reason why these mothers attended support groups was because they helped to keep up their hope (Ryan).

Other strategies identified included mothers overcoming their prejudices about mental illness (Wheeler, 1994) and accepting mental illness (Ryan, 1993). Furthermore, "getting away" by taking part in some enjoyable activity, and getting on with their lives as best they could were approaches used by mothers (Ryan). Also, mothers used going to the doctor as a tactic to overcome caregiver burden (Belcher, 1988).

Mothers with adult children with TBI. In this section, those strategies used by mothers caregiving their adult children with TBI are reviewed.

To begin, denial has been identified as a common coping strategy used by mothers caregiving adult children with TBI (Rees, 1988; Mauss-Clum & Ryan, 1981). (Both Rees and Mauss-Clum & Ryan are reviewed in the caregiving and caregiver burden sections).
Rees noted that in order to manage the caregiver burden and cope with their situations, mothers ignored the disabilities and pretended to family friends and themselves that everything was alright.

Other coping strategies identified by Mauss-Clum and Ryan (1981) included: use of support by "talking with a friend...[or] attending a Family Support Group"; use of prayer and meditation; and becoming involved in work (p. 168). A few mothers used tranquilizers, alcohol, vacations, and recreation. Two became authors, one wrote about resources available for the brain injured and the other was writing a book about family coping with brain injury. As discussed previously, it is difficult to generalize these findings to mothers of adult children with TBI because of the small sample size, the mixture of clients (traumatic brain injury, vascular accidents, and diseases), and it is not specified whether the mothers are caregiving the clients with the TBI.

The only study found that dealt exclusively with mothers attempts to manage caregiver burden related to caregiving their adult children who had sustained TBI was the work of Wilier, Allen et al.'s (1990). (This work is reviewed in the caregiving and burden section.) Wilier, Allen et al. used the Nominal Group technique to list the mother's coping strategies according to priority. The foremost strategy used was the development of a healthy outlook by "not giving up" (p. 171); a major strategy was the acceptance of their sons' limitations by abandoning many previous hopes and aspirations and then "developing a realistic appraisal" of their sons' capabilities (p. 171); and an important strategy was the maintaining of open communication between themselves and their sons; this strategy was considered necessary in order that the mothers could encourage their sons to participate in social activities. Lastly, educating the public about the effects of the TBI on their sons by pointing out the sons' capabilities as well as disabilities was considered a coping strategy.
Only the coping strategies of mothers who were caring for sons were identified by Wilier, Allen et al.'s (1990) Nominal Group Technique. Furthermore, even though the mothers were divided into two groups with six mothers of sons aged 14 years to 20 years and seven mothers of sons over 20 years to 24 years of age, the data have been compiled into one report. Therefore, a conclusion about significant coping strategies used by mothers of those sons 19 years of age and older cannot be made. For example, public education entailed dealing with educators in the public school system and this strategy would have greater significance for those sons who are in the school system. In addition, the study emphasizes how the mothers coped with the disruptions and losses related to the lives of their sons and not in their own lives. The only exception is that group leaders commented on the extreme devotion that the mothers had for their sons, and this devotion had not diminished even in those cases where the injury had occurred several years previously.

Summary

The extensive literature review places this study of mothers as caregivers to their adult children with TBI within the context of the present day caregiving knowledge. The depth and breadth of the caregiver studies that focus on caregiving to the elderly and particularly those with Alzheimer’s disease attest to the complexities and significance of the caregiver role. However, generalizing this caregiver research to the TBI population has to be approached with caution because of the difference in ages, developmental levels, and illness trajectories. The small number of studies about mothers who are caregiving adult children offer a glimpse into particular aspects of their caregiver role, but it is not clear whether these findings are partly or wholly applicable to mothers who are caregiving adult children with TBI. Even though many studies have emphasized that mothers willingly assume the caregiving role to their adult children who sustain TBI, no studies have been reported that have looked at their
overall caregiving experience. Studies that have included mothers have focused on the specific burdens encountered by the mothers as primary caregivers. Generally, a fragmented approach has been used to report findings that apply to other aspects related to the experience of mothers of adult children with TBI. Although the disruption to mothers lives as a result of having a adult children sustain TBI is referred to in the literature, the developmental difficulties that they face are not considered (Willer, Allen et al., 1990). Thus, research is required that will contribute to an understanding of the experiences of mothers whose lifespan expectations are altered when they become primary caregivers to their adult children who sustain TBI. This thesis was designed to provide such knowledge.
CHAPTER THREE

Methodology

A descriptive qualitative approach using an ethnographic research method of investigation was used for this study. Qualitative research methods are appropriate when exploring "problems about which relatively little is known" (Morse & Field, 1996, p. 2). The ethnographic research method is always the "the work of describing a culture" (Spradley, 1979, p. 3) from the emic or the "native's point of view" (Malinowski as cited in Spradley, p. 3). In nursing, the ethnographic method is used as a means to facilitate the understanding of the health practices and beliefs of a culture by gaining access to the insider's point of view (Morse & Field). For this study, culture is defined in a broad sense (Morse & Field) and is referred to as groups of individuals experiencing the impact of a common illness (Haggstrom, Axelsson, & Norberg, 1994), such as the mothers in this study who are experiencing the impact of their adult child's TBI. The ethnographic method was used in this study to facilitate the understanding of the experiences of these mothers.

Ethnography is rooted in cultural anthropology and dates back as far as 5th century B.C. (Aamodt, 1982) with the evolvement of several approaches (Morse & Field, 1996). For this study, "focused ethnography", a method favored by nurses, was used (Morse & Field). In focused ethnography, the "topic" of the research is selected before the "data collection commences" and the interviews are limited to the selected topic and surrounding event (Morse & Field, p. 127). Streubert and Carpenter (1995) state that focused ethnography is "an exceptional opportunity for nurses" to examine clinical practice issues (p. 114). Furthermore, according to Leininger (1985), the ethnographic research methodology gives nurses a systematic process for studies that are focused on understanding the lifeways and worldviews of cultures and families as well as individuals from their own perspective.
Therefore, ethnography was an appropriate methodology for this study that sought to understand the experiences of mothers who become primary caregivers to their adult children when they sustained TBI.

In this study, both the emic and etic perspectives were considered. According to Spradley (1979), use of the ethnographic method means that the researcher sets out to grasp the emic perspective by learning from the people being studied. Therefore, this researcher viewed the mothers of adult children who had sustained TBI as teachers. Furthermore, in ethnography, culture is viewed as a "system of meaningful symbols" (p. 6). Thus, this researcher used the etic perspective when seeking to understand the mothers being studied by searching for the meaning of the communications that were expressed directly through their language or indirectly through word or actions.

Because ethnography is an interpretive paradigm, the communications of the participants being studied and the researcher's observations are mediated (Agar, 1986), and concepts are developed (Morse & Field, 1996). In this study, the mothers' communications and this researcher's observations were mediated and concepts were developed that will assist in the understanding of the behavior of these mothers.

The Sample

In this study, nonprobability judgemental sampling was used (Fetterman, 1989). Participants considered to be representative of the subculture or group addressed in the research question (Werner & Schoepfle, 1986) were selected. Werner & Schoepfle state that a small opportunistic sample is adequate for an ethnographic study. Leininger (1985) and Fetterman emphasize that it is the quality of the sample as well as the intense interviewing that are more important than a large sample size. Pelto and Pelto (1978) support the stance that a few well chosen representative participants are adequate for an ethnographic study.
They state that "the careful selection of four or five persons who are representative of significant intra-community variations produce such high levels of inter-reliability that it is unnecessary to add more to the panel" (p. 88). The sample size of five is also supported by Fetterman. This size of a sample is considered adequate when the addition of more participants does not yield any new data (Pelto & Pelto). For this study, a sample of six mothers was considered adequate when the data were found to be saturated.

Selection of Participants

Because the success of an ethnographic study is dependent on a small sample answering a large number of detailed questions (Werner & Schoepfle, 1986), locating a "good informant" is paramount (Spradley, 1979, p. 46). Spradley notes five criteria that can be used for selecting a "good" participant: (1) thorough enculturation, (2) current involvement, (3) an unfamiliar cultural scene, (4) adequate time, and (5) non-analytic" (p. 46). By applying Spradley's formula to this study and by taking the researcher's situation into consideration, the following criteria were met by the participants:

1. The TBI had occurred at least three years previously. Rationale: The criterion of thorough enculturation was met.

2. Participants were all involved directly or indirectly in their children's care. Rationale: The criterion of current involvement was met.

3. All of the adult children with TBI had been independent prior to the injury. Rationale: The criterion of an unfamiliar cultural scene was met.

4. Participants were willing to take part in the study and were be able to articulate their day-to-day experiences to the researcher. Rationale: The criterion of adequate time and being non-analytic was met.

5. Participants were able to communicate in English.

6. Participants were accessible to the researcher, that is, the participants resided on Vancouver Island, the Vancouver lower mainland or relocated for interviews.
Selection Process

Although the researcher has the freedom to choose the participants for an ethnographic study (Werner & Schoepfel, 1986), "natural opportunities" and "convenience" determine which participants are selected (Fetterman, 1989, p. 43). The participants in this study were recruited in a variety of ways. For example, a letter (see Appendix A) was sent to: The British Columbia Brain Injury Association's (BCBIA) main office located in Vancouver; the BCBIA's branches located in Vancouver Lower Mainland, Victoria, Duncan, Nanaimo and Courtenay; and Victoria's Gorge Road Hospital's Outpatient Brain Injury Program. The purpose of the letter was to share the nature of the intended research. Follow-up phone calls were made to: (1) gain support for research project; (2) answer any questions about the project; and (3) to request participation in identifying potential participants. Additionally, to ensure that there was awareness of the research project, the researcher distributed letters to stakeholders attending the Pacific Coast Brain Injury Conference. And, explanations of the project were communicated in conversations with colleagues and community members.

A brief overview of the study was presented at a brain injury family support group meeting. Participant information sheets (see Appendix B) and sample participant consent forms (see Appendix C) were distributed to the members. Members were given the opportunity to ask questions. Participant information sheets and sample consent forms were also sent to BCBIA main office, the BCBIA's branches located in Courtenay, Nanaimo, Duncan, Victoria and the Lower Mainland and to the Gorge Road Hospital's Outpatient Brain Injury Program.

To summarize, participants for the study were accessed through British Columbia Brain Injury Association and its branches (ie. Lower Mainland, Victoria, Courtenay, Nanaimo, and Duncan), the Gorge Road Hospital Outpatient Brain Injury Program, and by
the "snowball" technique. All respondents received information about the study from the participant information sheet. Respondents were contacted by telephone to discuss the study, to provide the opportunity to ask questions, and to make arrangements for the interview. Written informed consent (see Appendix C), demographic information (see Appendix D), and permission to tape-record the interview were obtained at the time of the interview.

Description of Sample

Written informed consent was obtained from nine mothers. Of those nine mothers, one dropped out of the study, eight were interviewed, and six of those eight fit the criteria of the study. Of the two that did not fit the criteria of the study, the criteria of the age of the child and current involvement was not met. The sample (n=6) of this study length of time "post-injury" ranged from 3 years 9 months to 11 years, and the average length of time was 7 years 6 months. The adult children's ages ranged from 22 years to 42 years, with four out of six in their twenties. Four of the adult children were female. Five of the adult children were injured in motor vehicle accidents and one was injured in a fall. All accidents resulted in profound changes in the adult child. At the time of the injury, all were functioning independently. All were living in their mothers' homes with their siblings with the exception of one adult child whose only sibling had left the mother's home permanently. At the time of the interviews, three were living in their mothers' homes. Of the other three, one was living in a separate house only a few feet from the mother's home, one had just moved away but considered the mother's home the permanent base. The other had just started to live independently: the mother had been living in the child's home. Two mothers were involved with helping raise their adult child's children.

All mothers were employed at the time of the injury, three part-time and three full time. At the time of the interviews, one held a permanent full time job, one a temporary
full-time job, two were employed part-time, and two were not employed. Those who were permanently employed had taken jobs with considerably less responsibility than before.

Setting

Fieldwork is basic to ethnographic studies (Fetterman, 1989, p.41). Polit and Hungler (1991) define fieldwork as "a study in which data are collected... from individuals in their normal roles...as they normally function in real life" (p. 645). Whereas, Germain (1993) points out that for nursing, the setting for ethnography can be wherever significant and meaningful data can be obtained (p. 246). For this study, the interview locations and times were negotiated with participants. For some, the presence of the child in the mother's home and/or the need for respite services influenced where and when the interviews could take place. Ensuring privacy was the main concern for choosing a setting. Of the six participants that met the criteria, the locations selected included: two in the mother's home; one in the mother's parent's home; one in the graduate lounge at the University of British Columbia's School of Nursing on a Sunday afternoon; and two in an office at The Ministry of Health Burnaby location in the evening.

Data Collection

In ethnography, data are collected by multiple methods which include: (1) interviews; (2) participant observations; and (3) field notes (Morse & Field, 1996). Of these, the interview is considered to be the most important technique (Fetterman, 1989), and was the primary method used.

Interviews

Data for this study were collected by one face to face, unstructured interview, and in some cases follow-up phone calls were necessary to clarify information. Interviews lasted between one to two hours. All interviews were tape-recorded and all were subsequently
transcribed by the researcher with the exception of two that were transcribed by a typist.
While repeated interviews would have been ideal, time and resources made it impossible.

The ethnographic interview method described by Spradley (1979) guided the data
collection. At the start of the interview, as suggested by Spradley, rapport was established
by interviewing participants in a friendly fashion and at the same time the research agenda
was kept in mind by the researcher. The researcher viewed the participants as teachers or
experts and sought their information about their experiences couched in their own language
(Spradley). The information was obtained by a mix of open-ended questions, structured
questions and the questions were interspersed with friendly conversation. According to
Spradley, interviewing in this way helps to uncover the "cultural knowledge" of the
participants (p. 59).

Spradley (1979) emphasizes that the most crucial elements of an ethnographic
interview are "explicit purpose, ethnographic explanations" as well as ethnographic questions
(p. 59). By following Spradley's method, participants were informed about the purpose and
direction of the interview, therefore, the interviews were more formal than a friendly
conversation. Then, throughout the interviews, explanations were given as to why data were
to be tape recorded and transcribed, and why participants should describe their experiences in
their own words, and why certain types of questions were asked.

Spradley (1979) delineates the specific types of questions to be asked of participants
as: grand tour; descriptive; structural; and contrast (see Appendix E). In this study, the
grand tour question asked was, "What has it been like for you since your child sustained a
traumatic brain injury?". This question provided the researcher with a means to establish
rapport and to find out about the sequence of events since the time of the injury, as well as to
gain a verbal description of the cultural scene. A descriptive question was used to provide
the researcher with the opportunity to explore the participant/researcher relationship and to
determine the type of language used by the participant. The descriptive question asked was,
"Could you tell me about your experience of having your adult child live with you since the
injury?". A structural question gave the researcher a way to find out more about the
participant's cultural knowledge. The structural question, "What changes have taken place in
your life since your adult child with the TBI began living with you?", was asked once rapport
had been established. A contrast question helped discover the "dimensions of meaning" of the
event in the participant's world (p. 60). In this regard, participants were asked, "What is
the difference between your life before your child sustained the TBI and now?".

Although Spradley (1979) states that "Ethnography starts with a conscious attitude of
almost complete ignorance" (p. 4), Ryan's (1993) "A Lifetime of Mothering" conceptual
framework was used as a guide for data collection questions (see Appendix E). According to
Leininger (1985), "discovering accurate information" is foremost in ethnographic research,
therefore, use of a conceptual framework is not viewed as "tight" and "explicit" within the
research process (p. 41). Furthermore, Germain (1993) states that in nursing studies based
on ethnography, conceptual frameworks are used as a means for "examining...complex
human situation[s]" (p. 246). Therefore, in addition to the question format delineated by
Spradley, Ryan's conceptual framework was used to keep the interviews of these mothers
who were in complex human situations focused. Questions were couched on the disruption
and loss construct in Ryan's conceptual framework and addressed: the disruption in the
mother's relationship with the adult child; the disruption in the mother's life; management of
the disruptions; the loss of the child's potential; and the management of the loss of the child's
potential.
Participant Observation

Participant observation is essential in an ethnographic study with the phenomena viewed within the context in which it occurs (Morse & Field, 1996). To help the researcher comprehend the context of the situation, the ethnodemographic data were gathered at the beginning of the interview (see Appendix D). The record established the child's gender, age, date of injury, living arrangements, as well as the mother's employment status. Also, because behavior is context related (Germain, 1993), the context of the situation in which the interviews took place was noted (Morse & Field). That is, most participants were unwilling to be interviewed in their homes because of their child's presence. Because the mothers expressed discomfort about being interviewed in a public place such as a restaurant, and could suggest no alternative location, the researcher was responsible for locating suitable private places for those interviews. Time was another constraint for some because they were dependent on support services or family members to take over the caregiving so that they could be free for the interview. Some were only able to be interviewed on Sundays or evenings and that made finding a suitable, private place difficult because most known to the researcher were closed during those times.

The decision to take part in the study was carefully weighed by most participants. All adamantly emphasized that they only participated in the study because the researcher had a similar experience with TBI and would understand their situations. In most situations, participants interviewed the researcher face to face before deciding to take part in the study. Once committed, the mothers were cooperative and accommodating. During the interviews, the participants were open and receptive to answering all the open-ended questions and to sharing their experiences in depth. Although the mothers were aware of the researcher's personal and professional experience with TBI, they all readily assumed the role as teachers
and "expert" as they described their experiences. They revealed that they wanted the information to be used to help others who would be faced with the similar experiences in the future. Thus, the researcher's concern about developing a trusting relationship without going "native" (Leininger, 1985) was alleviated by the mothers' commitment to "teach" the researcher in order that the study could be used to help others.

Field Notes

A field note journal was used to keep an introspective record that enabled this researcher to "take into account personal biases and feelings, [and] to understand their influence on the research" (Spradley, 1979, p. 76). The distinct differences in the participants' experiences and the researcher's experience whose daughter sustained a TBI when six years old were recognized and recorded. The researcher was able to view the experiences of the mothers in this study as a new culture. The mothers' stories were so profound that the researcher had to take time to "recover" before analyzing the interviews in order to maintain objectivity. The field work journal was used to record the researcher's reactions to determine whether they biased subsequent interviews.

Data Analysis

In accordance with the ethnographic method, data analysis took place shortly after data collection was started. The primary focus in analyzing ethnographic data is to understand cultural meanings by searching "for the parts of a culture and their relationships as conceptualized by informants" (Spradley, 1979, p. 93). The method of data analysis used for this study was the constant comparative analysis outlined in Strauss and Corbin (1990). The use of this method to analyze ethnographic data is supported by Spradley (1979) and Fetterman (1989). The constant comparative method (Strauss & Corbin) aims to search for core variables or main themes that have three main characteristics"...it recurs frequently in
the data, it links the various data together, and it explains much of the variation in the data...." (Hutchinson, 1986, p. 118). In doing so, hypotheses are made as to how the data fit together to make the "best picture" of the culture being examined (Fetterman, p. 89).

Open Coding

By using the constant-comparative method, open coding of the transcript analysis was performed line by line in order to compare interactions, actions, and events for similarities and differences and ultimately to generate findings (Strauss & Corbin, 1990). Open coding is defined as "the process of breaking down, examining, comparing, conceptualizing, and categorizing data" (p. 61). Because this focused ethnographic study is a factor relating or level II enquiry (Field & Morse, 1996), the conceptual labels were developed by asking questions "What is this?...What's happening here?" (Germain, 1993, p. 243). Thus, patterns of behavior of every day life were conceptualized, and next, were grouped together to form categories that were defined according to their properties and dimensions (Strauss & Corbin). The categories generated in open coding were numerous, and were constantly compared with one another. They also provided the researcher with concepts that were tracked with other participants.

Axial Coding

The procedures outlined by Strauss and Corbin's (1990) axial coding were used following open coding. Axial coding is defined as "A set of procedures whereby data are put back together in new ways after open coding, by making connections between the categories. This is done by utilizing a coding paradigm involving conditions, context, action/interactional strategies and consequences" (p. 96). It is a complex process that involves both inductive and deductive thinking. That is, in axial coding, the researcher questions and explores the
properties of the categories and begins to build a relationship around the phenomena or core
category being focused upon.

Selective Coding

Selective coding is similar to axial coding but it is "done at a higher more abstract
level of analysis" (Strauss & Corbin, 1990, p. 117). During selective coding the core
category is identified and it is related systematically to the other major categories, and the
relationships are validated and refined. It is through the process of selective coding that the
patterns and webs in the data emerge (Perry, 1996).

Thus, conceptual labels such as "protecting", "watching over", "balancing", "setting
limits", "being flexible", "standing by", and "coming to the rescue" were identified as being
related to the same phenomena and were categorized together, and named "developing and
using caregiving strategies". This category was then related to other apparently similar
categories including "making the decision to caregive", "learning caregiving skills" and
"changing mothering styles to caregive". These categories were identified as subcategories of
"Becoming a Caregiver". This process became a major concept along with the processes
"Grasping Reality" and "Carrying Responsibility".

The core category evolved from analysis of the relationship between these three major
concepts and the "Intervening Conditions" of "Mothers' Individual Ways", "Availability of
Services" and "Economic Influences". The category of "Tactics Used by Mothers" with its
subcategories "Comparing to Put a Face on It", "Pulling from Within" and "Dealing with It",
were identified as action/interaction strategies. The subcategories "Gains" and "Losses"
under the category "Consequences" were the outcomes of the mothers' responses to the
central phenomena.
Finally, "The Experience of Enduring" emerged as the central phenomena of the study, and became the core category around which the other categories were systematically related.

Throughout the process of data collection and analysis a personal quality called theoretical sensitivity was required. Strauss and Corbin (1990) define theoretical sensitivity as "the attribute of having insight, the ability of giving meaning to data, the capacity to understand, and capability to separate the pertinent from that which isn’t. All this is done in conceptual rather than concrete terms" (p. 42). Theoretical sensitivity required a balance between science and creativity and was developed from a number of sources including literature, personal and professional experience, and the analytic process itself.

Rigor in Qualitative Methods

Assessing validity and reliability in qualitative studies requires different criteria than that used in quantitative research. In qualitative studies, it is the trustworthiness of the study that is sought (Lincoln & Guba, 1985). In doing so, the criteria of internal and external validity are replaced with credibility and fittingness and the criterion reliability with audibility and confirmability (Lincoln & Guba; Sandelowski, 1986). In this research project, several strategies were taken to ensure rigor and are grouped under the headings credibility, fittingness, auditability and confirmability.

Credibility and Fittingness

Credibility refers to the "truth value" of the descriptions and interpretations in the research findings and is determined by reporting the "perspectives of the informants as clearly as possible" (Morse & Field, 1996, p. 118). It is established when participants "immediately recognize" themselves in the research report (Sandelowski, 1986, p. 1). Fittingness is addressed when the findings fit the data from which they are derived and is achieved when
there is a "similarity between two contexts" (Lincoln & Guba, 1985). That is, when findings are taken into contexts with others who have had similar experiences, they can recognize themselves in the report. Credibility and fittingness were achieved in this ethnographic study in several ways. First, a written overview of the analysis was shared with all participants. Five participants were contacted and asked to comment on the truth value to ensure the validity of the data analysis. Second, the researcher kept a field journal that included thoughts and feelings about the researcher's interactions with the participants. This activity helped protect the researcher from "going native" or becoming so enmeshed that the experiences of the participants' and the researcher's could not be separated (Sandelowski). Third, the researcher recognized the "multiple realities" and both the "typical and atypical" elements were considered in order that informants' perspectives were reported as clearly as possible (Morse & Field; Sandelowski). Fourth, the results of the analysis were discussed with two other mothers in similar circumstances who did not take part in the study, and they were presented at an international brain injury conference to professionals working in the field, caregivers, and survivors so that they could determine whether the findings fit with their perceptions. Fifth, the multiple sources (interviews, participant observations, field notes, personal journal and literature review) were tested against each other to determine congruence among them (Sandelowski). These procedures were used to contribute to the "trustworthiness" of the study (Lincoln & Guba).

Auditability

Auditability is the criterion of rigor related to the consistency of qualitative findings (Sandelowski, 1986). To determine auditability, the researcher must present a "decision trail" throughout the research process. To do so, descriptions of the situation and justifications for all decisions made are reported in enough detail so that others would arrive
at the same conclusion. Accordingly, the final research report describes: (1) the reason why
the researcher decided to do the study; (2) the purpose of the study; (3) the description of the
participants and how they were selected; (4) the setting of the data collection; (5) the way in
which the data were collected; (6) the data analysis process; and includes (7) selected
quotations in the research report. Additionally, the researcher has made assumptions explicit
about the subject matter in order to interpret her own behavior in relation to the participants.
Furthermore, to ensure that the decisions can be followed, the researcher shared all steps of
the decision trail with thesis committee members both verbally, and in the final report.

Confirmability

Confirmability is the criterion of neutrality in qualitative research and is related to
freedom from bias in the procedures and findings. In this study, confirmability was
established when the criteria of creditability, fittingness and auditability were met.

Ethical Considerations

The research proposal was subjected to ethical review according to the guidelines set
forth by the University of British Columbia Behavioral Sciences Screening Committee. In
addition, the British Columbia Brain Injury Association's written agreement to assist with the
project was examined and approved by the screening committee. As well, ethical review and
approval was obtained from the Greater Victoria Hospital Society's Research Review and
Ethical Approval Committee.

Spradley (1979) emphasises that the rights, interests and sensitivities of the
participants must be safe guarded. To this end, participants were informed verbally and in
writing about the exact nature and intent of this study (see Appendix B). At the beginning of
the interview, the researcher reviewed the written informed consent with each participant
before they signed it (see Appendix C). The anonymity of each participant was assured and
protected. All participants were informed that their participation was voluntary and of their right to withdraw from the study at any time. Concurrently, participants were assured of their right to stop the tape recorder at any time or to have any section of the tape erased at any time. Audiotapes, transcripts and codes used to identify the participants were stored in a locked cupboard.

All interviews were conducted with the intent of promoting a relaxed, sensitive, informal and supportive atmosphere. It was not anticipated that there would be any harmful consequences for the participants. The researcher's experience in working with families of persons with TBI at a community level has been that the opportunity to discuss individual experiences with an attentive and accepting listener can be beneficial. However, it was recognized that the nature of this study requiring discussion of potentially emotional material stimulated strong negative feelings. Provision was made for the mothers to discontinue the interview in such circumstances. None of the participants requested that the interview be cut short. Qualitative research methodology allowed for the emotional responses to be addressed directly by the researcher. At the end of the interviews, the researcher debriefed the mothers to ascertain how they experienced the interview. All had found the interviewing process to be beneficial and/or non-harmful, therefore, it was not necessary to contact the BCBIA to get further support for the mothers.
CHAPTER FOUR

Results From Data Analysis

This chapter presents the results of the analysis outcomes of the data collected during the study from mothers who were primary caregivers of their adult children who had sustained TBI. The method of constant comparative data analysis as outlined in Strauss and Corbin (1990) yielded the core category "The Experience of Enduring" that linked the data collected. The conceptualization of "The Experience of Enduring" is portrayed in Figure 3 and its structure is explained. In the next section, the key theory categories are presented. To illustrate the grounding of the theory, representative data will be included.

Conceptualization of The Experience of Enduring

The central components of mothers' descriptions were the processes taking place within their lives when caregiving their adult children who had sustained TBI. These processes were found to be experienced at three levels: Becoming a Caregiver; Grasping Reality; and Carrying Responsibility. Through analysis the predominant theme that emerged was The Experience of Enduring these processes, and the conditions that affected their experience, the tactics used to manage the experience and the subsequent gains and losses. For this study, enduring is defined as "to continue in the same state...(to)...LAST; to remain firm under suffering or misfortune without yielding; to undergo...a hardship ...without giving in" (Mirriam-Webster, 1977, p. 377). In the figure, The Experience of Enduring is depicted within a circle representing how this experience is central to the mothers' lives. The Experience of Enduring is portrayed as the overarching theme of the three levels, Becoming a Caregiver, Grasping Reality and Carrying Responsibility.
INTERVENING CONDITIONS
- Mothers' Individual Ways
- Availability of Services
- Economic Influences

Comparing
In Order To
Put a Face On It

THE EXPERIENCE OF ENDURING
- Becoming a Caregiver
- Grasping Reality
- Carrying Responsibility

Pulling From Within

Dealing With It
- Inside Work
- Outside Work

CONSEQUENCES
Gains
Losses

Figure 3. The Experience of Enduring by mothers caregiving their adult children who sustain traumatic brain injury.
The mothers' descriptions revealed that three main tactics were used by them which contributed to The Experience of Enduring. These three tactics are categorized as Pulling from Within, Comparing in Order to Put a Face on It, and Dealing With It. When Pulling from Within, mothers drew from their inner selves to help them endure. Comparing in Order to Put a Face On It was a cognitive tactic that was commonly used by mothers to establish concreteness such as changes in the child or to validate their situations. Dealing with It was a term echoed by all mothers when referring to the deliberate behaviors they used to endure; This included Inside Work and Outside Work. Inside Work included the actions that mothers took to hold themselves and their families together when enduring the experience. Outside Work entailed what they dealt with outside their homes that was directly related to the experience. These three tactics were found to be distinct and separate from one another. In the figure, they are represented as distinct circles and are positioned as discrete domains that pass through the exterior of the circular core. Because these activities are specific to The Experience of Enduring, they are joined together in an outer ring which envelopes the central core. This representation underscores how these activities were used by mothers throughout The Experience of Enduring.

The uniqueness of each situation had a bearing on The Experience of Enduring. This uniqueness is captured in the diagram under Intervening Conditions. Mothers' Individual Ways, Availability of Services and Economic Influences all contributed. That is, the unique ways that the women enacted the mothering role, their knowledge base about TBI, their previous related experiences, and their unique abilities and comfort level in working with healthcare systems are all included in Mothers' Individual Ways. Whether services were available or not affected all aspects of The Experience of Enduring and the tactics taken. The mothers' experiences differed when appropriate services could be tapped into as opposed to
when services had to be fought for or could not be obtained at all. Economic Influences impacted on the purchasing of services, the degree of financial responsibility mothers had to assume, and fatigue levels of those who had to work. These intervening conditions are encapsulated in an arrow head and are aimed at the circular core, thus representing the direct impact that they had on The Experience of Enduring. This portrayal emphasizes the uniqueness of each mothers' experience.

When the women recounted the effects of The Experience of Enduring, Gains and Losses were outcomes which also had a direct bearing on their lives. To represent that two-way impact, the consequences are portrayed in the figure as being contained in a two-way arrow which is aimed out as well as into the circle's core.

Thus, in the figure, the elements of The Experience of Enduring are schematically represented. In the following section, their derivation will be explained.

The Experience of Enduring

In this section, representative data will be presented that will ground the core category, The Experience of Enduring in the data. To ensure some anonymity, the gender of the child referred to in the quotes will be altered. That is, him or her will be referred to as "hi/her"; his and hers as "hi/hers"; herself and himself as "hi/herself"; she and he as "s/he"; and when the child's name is contained in an excerpt it will be changed to "the child".

Enduring was selected because the mothers' descriptions indicated that their experiences were endured. That is, the continuous nature of the experience was exemplified in comments such as "ongoing need for support", "isn't going anywhere", "doesn't move on", "always there", "you are never away", "can't change it", and "demanding". As well, suffering and misfortune were clearly illustrated by statements that included "never be the same", "very devastating", "most devastating", and "most intense". Also, even though the
experience meant incredible hardships for these mothers, they remained unyielding in their commitment to their child. They described "feeling responsible" and that they "have to deal with it".

The main themes in the mothers' descriptions of The Experience of Enduring were the interplay between the three levels of processes taking place their lives; that of Becoming a Caregiver, Grasping Reality and Carrying Responsibility. Each mother's unique situation determined which process was predominant in their lives at any specific time. These processes will be addressed in turn.

**Becoming a Caregiver**

The process of Becoming a Caregiver was preceded by the mothers making a conscious decision to take on the caregiving. The amount of thought that went into the decision varied. Most recalled that before Becoming a Caregiver they deliberated on the specific arrangements that had to be made around organizing their work load. Also, they weighed the alternatives to their providing care. In doing so, the women considered what would happen to their child if they themselves did not provide the care. In the words of one mother:

"It would have been far easier to have hi/her out of the house then here. And yet, as hi/her parent you realize that s/he had to have some sort of a safe place to be. And, we were told s/he'll probably only vent in the presence of those people where s/he feels most safe... So we figured well I guess that's part of our role at the moment...I think we had to really work it through."

The mothers related how they had to learn how to be a caregiver to their children. Most found that caregiving information was lacking, and specifically, information on how to care for a child with cognitive and emotional deficits. All commented on how they learned how to care for through trial and error. Moreover, the children's needs changed over time, therefore, all were required to accommodate to those changes by learning different caregiving
activities. They referred to this learning process when describing their day-to-day caregiving activities. To illustrate this point, one participant said:

"You are kind of speculating all the time when they come and tell you something."

The women found the caregiving to be constant. For some the constant physical presence of their children was a factor. Another aspect was how their children and their children's needs were "always" on their minds. For example, one mother reported:

"When you wake up your problems are there. When you wake up they don't go away. They are there when you go to bed, and they are there when you wake up."

Some found meeting the never ending caregiving demands required a continuous effort. As illustrated in the next comment, even mothers whose children had improved physically, but still had cognitive and emotional deficits, found the caregiving to be all encompassing although having a different focus:

"It's different demands coming from a different place and I know that it's not going to end when they grow up because s/he is not going to grow up....That's the difference....Those demands are not going to change you know it's instability."

Mothers described their day-to-day caregiving activities and the unique caregiving demands. The type of deficits in their children determined the caregiving activities. Initially, most were involved with caregiving a child with physical deficits. Activities such as transferring, bathing, diapering, and dressing an adult child were required. That kind of care was no longer necessary for those children that had improved physically, but for others it was still required as exemplified in the following comment:

"There is so many aspects of it giving care....You've got the personal care that has to be done, and you've got the laundry to do, you've got feeding to do....Sometimes I would like to be just mum, but I'm, I'm like everything, I'm, I'm nursing, I'm hi/her dietitian, I'm hi/her therapist, I'm the cleaning person, I do medications, I do everything."
Some caregiving activities were exhibited by all mothers. That is, all took on the advocacy role for their children. All were actively involved in their children's day-to-day life either by coordinating all aspects of it, or by giving their children support and encouragement when their children tried new activities or when their children were able to pick up the pieces and start a new life. Also, all were concerned about their children's ongoing vulnerability. Because of this vulnerability, all mothers included protecting their children as a caregiving activity. As a result, they watched over and monitored both their children's behavior and their children's involvement in situations. Most intervened in those situations that they considered would be damaging to their children. One woman's description vividly portrays this point:

"Because of the head injury s/he no longer had control over that aspect...[sexual side of hi/her nature]....That was a difficult thing for us you know, to see that change happening to hi/her and then have to say, "NO you are not going out the door dressed like that...acting like that or with this person because there are sexual predators out there and you are sending hi/her all the signals that said come and get me."...You had to really watch because the danger was a very real danger...very, very real danger and yet s/he was not aware of it, s/he was like an innocent child."

The women described the multifaceted nature of providing care to their children with cognitive and emotional deficits. Most were required to be flexible in their caregiving in order to handle the unpredictability of their children's behavior or the situations encountered by their children. Some described how it was like being on a "roller coaster" with life being calm for awhile and then crisis happening. These mothers went from having to be deeply involved to backing off. Others went from crisis to crisis, and caregiving for them included guarded waiting. This is illustrated in the following comment:

"You could never relax. We could never relax. We never knew what was going to happen tomorrow....At one point we didn't know if s/he would have a tomorrow. I..I had to get used to the fact [that] because s/he was suicidal that the next time s/he went out the door s/he might not come back."
Some women described as caregiving activities those of setting limits or diverting or confronting their children when their children manifested inappropriate behavior. They were used only by those mothers who perceived that their children were able and ready to make changes in their behavior. Others endured the inappropriate behavior. One participant described confronting her child in the following way:

"It's like if s/he is not going to behave responsibly and show some respect for people then s/he can't be in the room with us, you know. You've got to have some space, that's what we have done....It involves a lot of confrontation with hi/her and uhh trying to get hi/her to understand...why s/he has to do things you would like hi/her to do and why s/he can't just do this because there is other people involved."

In situations where their children had duel needs, a need to be treated like an adult, and the need for caregiving, mothers balanced being there and being supportive to their children with being firm without crushing their children. The following comments demonstrate how the women struggled to balance their children's needs:

"It basically is having this adult here that needs to be treated like an adult, but that doesn't have adult skills, you know. It's very...very difficult. And, uhh you know, it is hard to respect them for being an adult and still provide them with the support they need. It's...it's very, you know, they..they are devastated from being an adult to being a baby."

"The greatest challenge of the whole experience, I think, has been to safeguard that person without smothering...umm to...to be supportive, but know when to step back and be unobtrusive and let them try their own wings....It's like being a mother of a young child learning how to walk."

In situations where the women stepped back to let their children try "their own wings", this letting go was clouded with trepidation that their children's welfare would be compromised. When children encountered problems, the women reacted according to the degree of difficulty that their children faced. That is, the mothers came to the rescue only in extreme situations. One participant's description vividly portrays the degree of difficulty that was encountered before rescuing her child:
"S/he is an adult. S/he knows she is an adult. S/he wants to do what s/he wants...but, we can't always let hi/her do that because of safety issues. So it...it was difficult....We uhh just kind of went along and let hi/her...[live independently]....But then,...I got to the point where I couldn't deal with the ton of it anymore because I couldn't handle being phoned from the police station all the time because s/he had been arrested. And, I couldn't deal with tens of thousands of dollars in lawyers' bills."

Most mothers included the caregiving standing by their children when their children's social deficits caused social isolation or social problems. Some deduced that their children had to learn how to handle these situations on their own. Those women stood by and gave their children space in order that their children would have the opportunity to learn from the consequences of their actions. For example, one participant said:

"I think s/he is wanting to have someone s/he can trust, to bounce something off of....S/he will tell me, "Mom, I don't know what to do"... But one of the things...I have had to do, is to step back and let hi/her experience the consequences of hi/her choices."

Most women noted that their previous ways of mothering their children no longer applied; instead they had to change their methods according to their children's needs. In doing so, they used approaches that they never would have used in the past. That is, some women who had prior to the injury been supportive and helpful if their children floundered now found they had to hold back so that their children would learn from the experience. Some became rule makers and put constraints on their children, whereas in the past they had cultivated self-sufficiency in their children. Most found that their previous ways of confronting their children when their children manifested inappropriate behavior had to be modified. The following excerpt illustrates this point:

"You have to learn to handle them so differently,...because you don't know. Before what would have been a predictable outcome of their behavior, today is very different."
Mothers overall found caregiving their changed children to be the most difficult and challenging experience of their entire lives. Some described the experience as being the “most intense” and the “most devastating” thing that had ever happened to them. The enormity of the difficulty is evident in the following comment:

"It's not a job I would have chosen; it's not a career I would have chosen, you couldn't have paid me enough money to do this."

**Grasping Reality**

The next level of The Experience of Enduring was the process of Grasping Reality. Mothers found that the full reality of the situation did not occur at the onset of caregiving. As illustrated in the next comment, they noted that initially they were not in denial about the impact of the injury, but they had no idea what lay ahead for themselves:

"From the minute we walked into the hospital room and saw hi/her that is a pretty graphic slap in the face of what reality is....We never had a problem with that one [denial]. Umm, we didn't know at that time that there would be so many years of care and sacrifices there was going to be."

All mothers found that it took a while before they realized the full impact of their children's injury on their lives. One woman said:

"And it takes awhile before you get to the point where you realize that this isn't going anywhere, you are never going to get rid of it, you just have to accommodate it...It will go on for the rest of hi/her life."

The reality of the changes in their children and their need for ongoing caregiving left mothers with serious concerns for the future. What might become of their children weighed heavily on both those who had children living independently and those who had totally dependent children. This concern is exemplified in the following comments:

"The concerns for the future is very...very much there....As a mother you think is s/he going to be able to do this? What is the next thing that is going to put hi/her over the edge?"
"[It's] very frightening to think of what the future is...I'm getting older too. It frightens me as to what will happen to hi/her."

Mothers worked to come to terms with the trauma, their changed children, and their caregiving situations. They struggled to accept the accident. Part of their struggle was how suddenly the accident had happened. Most gave vivid descriptions of the details of the accident, the initial condition of the child and their feelings around the event. They reacted with emotion when discussing the event. Some remarked on how their thoughts around the accident triggered feelings of "intense fear" of losing other family members, "nervousness", and made them feel emotionally labile. Accepting the trauma and moving on was recognized by the women as something that had to be done, but it was difficult. One participant fervently described the difficulty:

"It is a very.. very devastating, it can be very devastating type of accident to go through. The ramifications of dealing with that, but, I think you have to learn to accept it you can't change it....There is a lot of feelings it brings up....Our lives have been changed forever as a result of the accident, but I am not going to let the accident hold me in its power...you know. You can keep on living that way referring back all the time to the accident and everything. In order for healing and wellness to come to us, we've got to be able to release that...otherwise you just go down....You would be engulfed by all the ramifications of it."

For most mothers the events surrounding the accident had a bearing on their acceptance of the traumatic event. Some were faced with working through their feelings of having in some way contributed to the accident by something they had done. Others considered their children or others to be responsible. When children were found to be "totally innocent", the dilemma of accepting the accident was compounded for those women. The next comment illustrates one woman's position:

"A tragic accident that's what we have to deal with....S/he was in the wrong place at the wrong time....Maybe had s/he done this [to hi/herself], I might have been able handle it better, but s/he was totally innocent, you know....I raised hi/her for twenty one years and somebody instantly took all this all this away...and, it is hard to accept."
The women found that they had to face the reality of having profoundly changed children, and they recognized that it was necessary that they accept their children. Taking the approach that their children were new persons in their lives, helped most women to accept their children. Some had to come to terms with accepting their new children with extreme behavior problems and found building a new relationship difficult or impossible to do. Others worked to accept their children with catastrophic physical deficits. This reality is exemplified as follows:

"It was a very real sense of a very different... very different person, and there is the whole issue of acceptance of the existing person too."

The women had to face the reality that their children would need ongoing caregiving. Most realized that their children had a need for continuous support because of their children's permanent disability. The comment by one participant demonstrates the impact of that reality:

"I would be happy if I didn't have to, but you know it isn't going to go anywhere, so."

As will be seen in the next section, because of the reality of their children needing continuous support, the women carried this responsibility.

Carrying Responsibility

The process of Carrying Responsibility for their adult children was totally omnipresent even though it was years since their children had sustained the trauma. The women carried the responsibility for their adult children's safety and life. This enormity was evident in their descriptions of their children. Based on what they found their children's level of functioning to be, the women attributed a chronological age to their children. Those ages consisted of being an infant or a baby or a young child in an adult's body, as well as being much younger or a teenager. Furthermore, a striking component in most descriptions was that their children
continued to function at or near those age levels. And, even when improvements in functioning levels were described, those mothers emphasized that their children still functioned at a level far below than what is normally expected of persons of the same chronological age. Moreover, carrying the responsibility was made even more complex when their children’s permanent, severe deficits were added to the mix. More explicitly, one child was described as being profoundly physically and cognitively disabled and another severely cognitively impaired. The remainder manifested varying degrees of impaired executive function, emotional and social problems, and selective cognitive deficits. The enormity of the responsibility is illustrated by one mother who said:

"I mean totally, absolutely totally [dependent on me]. I mean even my husband works on day shift and he leaves home at five thirty, well eight o'clock he phones. I said to him, "you phone just to make sure I haven’t died in bed, I mean she is going to lay there till you get home at three o'clock, you know, you know, phoning just to make sure that I’ve gotten up this morning, you know, I haven’t say died in bed, because I think it would be a horrible thing for her if she’d have to just be laying there all day long because she can’t do anything".

Carrying Responsibility was directly related to the women feeling responsible for their children’s care; Giving care was something they had to do. Feeling responsible was also the motivating factor for their taking on the initial responsibility for their children’s care, and these feelings had endured. Furthermore, even when there were spouses present, the women carried most if not all of it because of these feelings. The comment by one participant illustrates how feeling responsible was all-pervasive:

"That s/he is there and I.. I feel responsible. I find that is the big part! It really influences your life when you know you have responsibility for this person."

Some mothers' feelings of responsibility extended towards their adult child's children. They helped with the raising of those children.
The women were comfortable about relinquishing responsibility only when their children were in situations that they considered suitable. Consequently, the relinquishing of responsibility tied in with available suitable alternate choices. Some got respite from shouldering all of it when adequate lawyers or health care workers became involved with their children's care. Others could let go of carrying the responsibility when they felt comfortable that the relationships their children had developed were supportive. Whereas, others were actively seeking something suitable for their children. The following excerpt illustrates this point:

"I have to get hi/her settled. I've got to get the support system there for hi/her because parents are not going to be there forever....I know we got to do this, but it is difficult to get it in place."

Mothers were resigned to continue with the responsibility if suitable alternatives could not be found. Even those who thought their children had a suitable alternative were resigned to take it on again if the alternatives did not work out. The women recognized that if they had to carry the responsibility it would be for the rest of their lives or until they could not do it anymore. As illustrated in the following comment, they preferred that their children be settled into something suitable and thought it would be best for their children and themselves:

"I guess what I need is for hi/her to have moved out into SOMETHING!! that s/he can cope with. I don't know what, that is what we are trying to find out right now. But, I just need that....And, I think...umm I don't want hi/her to live with me for the rest of my life.. BUT! if that happens..that would happen..you know that would be that."

Mothers who felt comfortable about alternate situations were greatly relieved about being able to relinquish the responsibility. Carrying the responsibility had been a heavy experience to endure. The enormity of carrying it became clearer to these women when they were freed from it. The following excerpts reveal just how liberating it was when they were released from carrying the responsibility:
"I never realized...how much of a load was lifted off of my shoulders. S/he's managing; s/he's doing it."

"I see a light at the end of the tunnel."

In this section, representative data have been presented that grounds The Experience of Enduring and the three levels of processes that of Becoming a Caregiver, Grasping Reality and Carrying Responsibility in the data. What follows is the tactics identified in the data that were used by mothers when enduring the experience.

**Tactics Used by Mothers**

Tactics were created and used by mothers when Enduring the Experience. In the data, three tactics were identified that were used to handle, manage and carry out the processes of Becoming a Caregiver, Grasping Reality and Carrying Responsibility. Pulling from Within, Comparing in Order to Put a Face On It; and Dealing With It are the three major tactics mustered. In the following sections, these tactics will be presented in that order.

**Pulling from Within**

The first tactic, Pulling from Within, refers to how the women drew upon their resources of the past relationship with their adult children and their philosophical and belief stance to endure the situation. Most recalled how the past relationship had been "good" and how they "enjoyed" and "loved the child" and had "adult to adult friendships" with their children. Others recalled how their children had been experiencing bad times. Some described the positive personality traits of their children that had made the relationship "special" such as "no problems, good kids good in school", "enjoyable", and "phenomenal sense of humour". Most emphasized that their children's new personality traits were an antithesis to their previous self and these changes made caregiving difficult to do. However,
they gained strength from the past relationship to manage the present situation. Two mothers explained:

"I love hi/her and, and, umm I was there when s/he was healthy and I feel its part of my job as a mom to be there when s/he is ill."

"S/he was different, but I always.. I always.. I still enjoy the person that s/he had become. I was always very close to hi/her so it wasn't, uh I guess a huge change."

Most mothers used their knowledge of their children's previous personality traits to help them endure. Some looked for and found traits in their changed children that had made their past relationship a good one. Others found that they could endure difficult situations by basing their caregiving decisions on that knowledge. For example, one mother used the knowledge of her child's previous personality traits to handle her child's potentiality for suicide:

"There is the whole scenario that comes in around depression, the suicide thing...s/he hasn't attempted it, and I doubt very much that s/he would. I think s/he has always been stable enough."

By drawing upon personal beliefs and philosophies, the women gained strength to become caregivers. Most held the convictions that they could provide the best place for their children and that their children would have a better quality of life. A safer and more loving environment, stability, a "good family life" were some of the attributes that some believed their caregiving would provide. Furthermore, as illustrated in the following comment, mothers drew upon their personal beliefs when dealing with changes in their children:

"I would not have done this [raise children] to raise up little clones of myself and bask in the glory of their successes or anything like that, to me, that is just a little bit warped....Our concept of the family circle is not who we thought you should be, not who you thought you were or what you give or contribute to society or whatever. It..it is merely that sense of love and being there and we never lost that."

Most women found that their basic nature and their personal perspective of life gave them strength to endure. Characteristics such as positive identities or outlooks, feelings of
love, "take it as it comes philosophy" were credited by mothers as contributing to their
Enduring the Experience. For example, one participant reported:

"I have been really thinking about this, and I think there is a real sense if I... if I
hadn't had a positive identity I think I would have been so shaken and devastated that
who knows what might have happened to me as a person, you know."

Some mothers drew from their spirituality and religious beliefs to endure the
experience. Prayer was used at the initial stage of the injury and later on to find answers
about their situations. Religious beliefs helped these women to alleviate their concerns and to
give them hope. This is exemplified in comments by two mothers who said:

"Whenever s/he stalled off at a point and... and uhh nothing was happening for months
on end,...I would go, "Well God this is going on forever [is] this what I have to-
do?"...And then,...that is where the prayer part came in, where it really, really
reassured me that, "No!...that isn't the way it is going to be. You have to have that
hope."

"I didn't have an ounce of energy left to give to anybody. I felt like I was in a
bottom of a well, no water, no escape, no way out, and I had no resources. But,
being a Christian I also know that if I could trust Him enough to realize that He knew
exactly where we were going and what we were... what was ahead, and what had been
behind...I could just trust Him that it would uh things would work out, just taking
moment to moment."

Most women "firmly" believed that "things happened to people for a reason" and that
there had to be a reason why the trauma had occurred. Some were trying to figure out the
reason, but the reason was not clear. Others were convinced that one day they would "really
know why this happened". For example, one mother speculated:

"I like to think that there is more than random chance working in life here....I, I like
to feel that yeah there is a better purpose in life and that the reason I went through
this is because I was the kind of person that would not be broken by this and that my
family is the kind of people that would not be broken. You know that old adage that,
that what doesn't kill you makes you strong."
Comparing in Order to Put a Face on It

The next tactic, Comparing in Order to Put a Face On It, was heavily relied upon by all mothers. The women measured their children's losses by comparing the overall present state of their children to their pre-injury children. Some of the differences described by them were the changes to the child's "physical abilities", "academic abilities", "goal focus", "sense of humour", "verbalization skills", cognitive "process" skills and "fatigue levels". By using this approach, they emphasized the "death" of their previous children and came to terms with the reality that their post-injury children's lives would "never be the same". One participant's description vividly portrays how comparing was used to validate the magnitude of change in her child:

"This is like another child because s/he doesn't look like s/he did before, s/he doesn't act like s/he did, personality sort of thing. I mean the only thing the same is hi/her name and they tell me this is hi/her....S/he's not there like s/he was before."

The women also used comparisons to gauge changes in the condition of their injured children. By contrasting their children's present condition to that of a previous time in the post-injury phase, most realized that some improvements had occurred. Improvements to their children's physical condition were noted by most mothers. Some also found improvements to their children's ability to plan and handle their day to day lives as well as a lessening of their children's crisis. However, by doing this, most women also recognized that the improvements were not profound. The following excerpt illustrates this point:

"S/he couldn't cook this much last year. S/he couldn't figure out what to eat last year...You just have to look on hi/her advances and you know they are not so quick.. You have to look back a year or two years to realize that you are going ahead...s/he improves. It is not great."

Others noted declines in their children's situation by using this approach. Behavior deterioration and increased "social isolation" were identified by those mothers.
Mothers also compared their children's condition to others who had sustained a TBI. By doing so, the women established that their caregiving situations were not so difficult after all or that they were more difficult than what other mothers were experiencing. When some mothers compared their children to others who had been less severely injured and observed that their children had less difficulty functioning, they "felt lucky" or "fortunate" or "thankful". As illustrated in the next comment, some were grateful that their children's behavior problems were not as severe as others:

"We didn't see physical violence coming from hi/her like some people I heard of. Their kids just changed, they just BOOM throwing things or whatever."

Comparing whether or not caregiving children with physical deficits was more difficult than caregiving children with behavior deficits was another area frequently referred to by those women whose children had behavior problems. They emphasized that although their children manifested few physical disabilities their children had "all sorts of social problems", "coping problems" and in some cases "abusive type behavior". Some had found the initial caregiving experience when their children had physical problems to have been far easier. For example, one woman said:

"I think that in some ways its more stressful and harder to deal with that mental alertness that we had to maintain uhh was harder than being there to change a diaper or...a tube back in when s/he pulled it or something....I found it easier to deal with the physical aspect."

The women placed their caregiving situations within a context by comparing. Some equated the caregiving to holding an outside job and in doing so validated that, for them, the caregiving was harder work. Comparing helped in that they realized the situation was hard to endure. By comparing caregiving the child with a TBI to caregiving someone with an acute disorder or a terminal illness, some verified the constancy and uncertainty of the situation. As presented previously, all compared their adult children to a baby or younger child to
validate their ongoing involvement in the caregiving. But, most mothers also compared the
demands of caring for their children when they were young to caregiving these children in
order to emphasize the difficulty. They considered this caregiving to be "more than the
average load" or "tougher than the average challenge" or "a whole lot different kind of busy"
with "days that are extremely intense". They also compared their children to their other
children to validate the difference. That is, their children did not "move on". One
participant explained her position this way:

"I don't think of my other [child] as like well when I am not here what's going to
happen because I know s/he can function and s/he can work and s/he can make a
living and look after hi/herself. But, this one... I really.. s/he's always there."

Mothers also used comparing to get encouragement that would help them in carrying
responsibility. To do so, some compared aspects of previous caregiving dilemmas that they
had mastered. The next comment exemplifies how comparing helped one woman to endure
when she felt discouraged:

"When you get discouraged and think about well Okay like six months ago or a year
ago we thought we would never get past this particular crisis and now we are doing
this. And, of course there is another one out there....Like when you are looking at it
and [think] "Oh this is I am so, I am really just so sick of this". I needed
something."  

Comparing was also used by the women to validate their personal state. They noted
improvements such as "stronger emotionally", "not as stressed", "things are better...definitely
improved", being able to be "quite active now" and not having to "deal with a particular
agency". They established the differences between their "ways of grieving" and Dealing with
It to their other family members by comparing approaches. As illustrated in the following
comment, most compared their freedom to take care of themselves to other people's freedom
and in doing so got a realistic perspective on their personal circumstances:
"Taking care of me, I don’t have the facilities to go away for weeks like other people. Relax by, by going away for a week or two weeks. I am not able to do that."

Mothers contrasted services for, knowledge of and societal attitudes towards persons with TBI compared to other disorders or disabilities. Most noted that even though the numbers of persons with TBI "continues to increase daily" the availability of services did not measure up to those available for other disabilities. This dilemma was described by one mother who said:

"It is very frustrating to know that...s/he needs to see a psychiatrist or.. but s/he doesn't have the money to pay for it. Well somebody who is on GAIN totally ...is entitled to all of this for free, is entitled to counselling for free umm rehabilitation services and occupational therapy."

The women also compared people's general knowledge about TBI to knowledge of other physical disabilities. The following excerpt illustrates this difference:

"People just don't understand head injury and don't try to. It seems like they have a lot more physically disabled children that weren't a behavior problem. It makes a difference when you got the problem."

They also used comparisons to attest to the lack of compassion that society had towards persons with TBI. For example, one mother said:

"If you lost your leg, people wouldn’t expect you to walk... but people expect you to use your brain..even though... [there] is the injury there."

**Dealing With It**

The third tactic, Dealing With It, includes the deliberate behaviors carried out by the mothers in order to endure the experience. Under this category two subcategories were identified: Inside Work; and Outside Work.

**Inside Work.** Inside Work includes the steps that the women took to hold themselves and their families together in order to endure the experience. In holding themselves together, they worked at looking for positive aspects in the experience. This work was accomplished
by constantly looking for the "good things" in their children or the situation or by reframing aspects of their individual experiences. Therefore, not all mothers reframed the same experiences. Those mothers that reframed the accident scenario felt lucky about the appropriate help that had been given to their children at the accident scene. Those that reframed the ongoing post-injury phase felt fortunate about receiving help that had made the experience a little easier. And, those that reframed aspects of their children's deficits looked for something positive in their children such as finding an "inner beauty" in their children or feeling blessed that their children were in denial because their children would not suffer as much.

Furthermore, most women looked for the positive to deal with their caregiving experience. Some said that the caregiving experience had given them positive feelings such as "feelings of peace", or of having "done the right thing" or of pride for having given "good care". These positive feelings were experienced by those mothers that were helping raise their children's children as well. The following quotes illustrate how the women reframed the experience into something positive:

"I haven't got ten years invested in my career now....But, after seeing my child hooked up to all those monitors, all those tubes hanging out of her, all those bruises, all those cuts, all this mass of trauma to her, I don't give a damn about the career that was lost...because I think that I.. I have fundamentally fulfilled the best career I ever could in my life."

"I think the last four years have been hell. It would have been the most painful experience in my life to have lost hi/her..It really would have been...that would have been just like you have ripped my guts out."

To hold themselves together, all mothers worked at taking care of themselves. They recognized that it was essential, but all were constrained by their individual circumstances. Most had to learn how to work through those constraints. Constraints for some included finding substitute caregivers so that they could do something just for themselves. In the end,
all had found their own way to take care of themselves. The comment by one woman describes the work involved in taking care of herself:

"You umm learn to deal with whatever you can get,... what's there you have to use...So, uhh, I have to do what I can do and it's difficult...My concept of taking care of myself is different than what other people would [do],...with what people expect....You just take whatever you can get, it is very important for people to learn to do that but it is hard to learn."

The women took part in activities that suited their preferences as well as their circumstances. Consequently, several unique activities were identified such as riding a horse, getting a cell phone or having a manicure. Also, some activities were found to be used by most. These activities included having a break from the situation as well as seeking out the company of understanding people. In this regard, both understanding friends and support groups were sought out. In addition, some described "having a good cry", "weeping" and "shouting" when alone helped them deal with the experience.

Some took care of themselves by setting limits. These women had to work through their personal constraints which comprised of the expectations they placed upon themselves. In doing so, they had to recognize personal limits and take actions to not overstep them. However, as exemplified in the following comment, most found it hard to set limits when it came to caregiving their child:

"When you are a parent it is very difficult to... to uhh put your children on the side and take care of yourself."

As a means of taking care of themselves, some mothers took measures to protect themselves. Some purposefully used avoidance and denial strategies. These women revealed that they deliberately would not think about the full ramifications of their situations. Others "built walls" to save themselves from being "ripped apart" when they were targets of their children's abusive behavior. This is exemplified in the comment by one mother who said:
"I built walls...for the first time in my life...I had to protect myself you know...I kept getting my heart kept getting ripped out you know...there was some big walls that just about did me in at times...It was a protective mechanism I know that, to guard me from getting hurt....I just felt like my heart would be ripped out."

Protective mechanisms were also used by the women when they worked at holding the family together. They found that the "massive trauma" and the child's needs and/or behaviors "disrupted" and "upset" the "entire family". They "protected" family members by handling the situation and by encouraging other members to go on with their lives. Also, some worked at protecting their spouses. These mothers found that either their spouses could not "deal with the situation" or they "were going through [their] own grief" or they were "suffering from stress". The next excerpt illustrates how one woman protected her spouse in order to protect the financial situation of her family:

"It stresses him out and so its like I have to hold my composure for two of us...not just myself....I don't want to put too much on his plate he tends to handle stress differently than I do...so if I can handle it I do...I don't want anything to happen to him....so its kind of like I am trying to protect him...because he goes out to work...One of us had to."

Furthermore, most mothers strived to promote "somewhat of a normal life as possible" for the rest of the family. They kept up family traditions as well as their other children's routine activities. The challenge of holding the family together by working at providing them with a "normal life" is evident in the next statement:

"You can't make the rest of the kids suffer, that's the wrong word, but lose out because this person requires so much attention. It's very challenging!"

**Outside Work.** Outside Work entailed what the women dealt with outside their homes when Enduring the Experience. In this regard, most had to "take charge" and actively seek out services. They had to "advocate" on behalf of their children and "make decisions" regarding services. They also searched for solutions by joining societies such as brain injury associations. Some found that to get services they had to stir things up even though they did
not want to. They found that if they didn't then "nobody else would" so they "just did it".

When attempts to get help for their children were rejected, some mothers tenaciously fought bureaucracies. For example, one mother said:

"I really get backed into a corner then..then..then uhh I begin to fight dirty and.. I..I try to do things the proper way but when it gets stretched to the point that where I can't stretch anymore then I will go after a government department...and uhh manage to get something."

Some mothers found they were "not listened to" when they spoke up on behalf of their children. One woman described her experience of not being listened to:

"You go into a meeting with people and they have already prejudged the situation based on their prejudices. They do not hear anything that you try to present to them. You know. They are so fixed on what they know what the answer is...And, I have always been.. my big bug-a-boo that if you haven't walked in my moccasins you can't tell me where I am at, you can't tell me that you know how to fix the problem if you never experienced the problem."

Included in the Outside Work was the litigating experience that all mothers had dealt with or were dealing with. They were thrust into the responsibility of making crucial decisions that would have an impact on the remainder of the child's life at a time when they were "already in a traumatic situation". The women were involved with "finding lawyers", taking the child to "expert witnesses", dealing with "pressures" from insurance companies, going "into court", "arbitrating", making decisions around "committeeships" for the child, "deciding on settling", "appealing judgements" and handling the "public trustees". Most had concerns about the enormity of the responsibility given the nature of traumatic brain injury.

The comment by one mother illustrates this point:

"Dealing with the court case you know - a lot of things - and brain injury, there is a lot of uncertainty"

The difficulties experienced when having to deal with the litigation experience was expressed by one women who said:
"It's having a lot of other people in your business...It wasn't something that we chose...It's forced on us so, I mean we just couldn't say I don't want to deal with this and walk away. I mean we had no choice and um, you just hope you make the right decisions...It's too much for me at times...I have to...I wish that I didn't have to."

Mothers' overall litigation experiences varied. Some were still involved and others had already gone to arbitration or had settled out of court. Some found the experience went smoothly. All mothers whose children had received the financial compensation were distraught over the amount of money that their children did or did not receive. This distress is illustrated in the following comment by one participant:

"But when the judgements...when they come down, you know or uh the settlements, they can't ever compensate for the issue around the loss...And you know when is enough...enough..you have to sort of say. S/he didn't get anywhere near the settlement that, you know, we hoped for."

Another aspect of the mothers' Outside Work was bridging with society. The women found society "a hard thing to deal with". They found that society's perceptions of the situation were dependent upon the "outward appearance" of the child and based on a reference point that did not include the ramifications of TBI. Thus, those children that looked alright on the outside had expectations placed upon them, whereas those children that exhibited "embarrassing" behavior but were considered "okay" from a "head injury" standpoint were rejected by society. As a result, the women were distressed by society's attitudes towards their children. One mother described this plight:

"Society doesn't have a clue!...Even after all these years with fighting to get this recognition,...if your leg ain't broke they are not there for you....They are strictly physically oriented, they do not understand the concept of head injury....S/he found out early on, s/he said, "they will bamboozle you"...So, it is absolutely imperative that...[they]...take a strong advocate that goes with...[them]...everywhere."

For themselves, they were faced with comments by society that included "death would have been better", "I don't know how you can cope with that" and "there is nothing the matter with hi/her, s/he is fine now". To deal with society, most developed a facade. They
would act "normal" in front of people even though they felt heart broken inside. Most found that they had learned to go along superficially or say nothing when comments were made even though they found the comments to be hard to take. The frustrations experienced by the women when dealing with society is evident in this next quote:

"You just get to the point where you realize you cannot explain it anymore to people that don't understand the ramifications of this type of injury."

In all, mothers dealt with the Inside Work as well as the Outside Work on a day to day basis. As illustrated in the following comment, most took "each day as it comes" and dealt with things as they went along:

"I don't really stop and think about [it], you're sort of dealing with things all the time...so I don't know that I've given it a whole lot of thought, you just, you know, you just keep dealing with everything that is thrown at you everyday."

In this section, data that supports the three main tactics used by mothers when Enduring the Experience have been presented. The findings revealed that the tactics used by mothers fit into the three major categories: Pulling from Within, Comparing in Order to Put a Face On It, and Dealing With It. However, as will be seen in the next section titled Intervening Conditions, each woman's individual set of circumstances made each experience unique.

Intervening Conditions

Intervening Conditions are the "structural conditions" that have an impact on the situation (Strauss & Corbin, 1991). For this study, the Intervening Conditions are the individual sets of circumstances that provided the underpinnings for and influenced the mothers' Experience of Enduring. Three categories were identified: Mothers' Individual Ways; Availability of Services; and Economic Influences. What follows is representative data that supports the selection of these three categories.
Mothers' Individual Ways

Mothers' Individual Ways refers to the individual attributes that each woman brought to the situation, attributes that made each experience unique. Several individual ways were identified. Firstly, how each woman enacted their mothering role underscored their individuality. Most mothers considered caregiving the adult child to be an obvious part of the mothering role, mainly because "nobody looks after your kids as good as you do". However, each mother emphasized that in this situation they considered their mothering style to be unique to themselves. They carefully described how their style had helped them endure certain aspects of the experience. Attitudes about "doing" for their children, how they made decisions, how they approached situations, and in some cases how they strived for perfection were some of the styles contained in their descriptions. The following quotes illustrate how the women viewed their mothering style to be unique:

"Well [even though] there are similarities, and even identical sets of circumstances, because human beings are so unique the way you come onto it is different and that is not wrong."

"Now, when we are going back and talking about parents you know, I found a lot of the parents...that I connected with at any rate, each of us handles things differently."

Secondly, mothers' individual abilities of handling the system as well as their abilities to communicate with professionals and healthcare workers influenced the experience. At the outset, some felt overwhelmed and disappointed when they encountered drawbacks while working with the system. They had to learn how to work it. Others had few expectations from the system and simply dealt with it when they came across obstacles. For example, one woman said:

"I know that if somebody is going to help me, it's going to be me not that my support system doesn't work, but I am responsible for me...If I expect something from people maybe it will work out but, if I don't put something into it then I am not going to get something back."
Similarly, mothers' overall ability and comfort level in communicating with professionals varied. Having this ability was significant because of the numerous professionals and health care workers they all had to deal with. And, not only were the women required to provide them with understandable descriptions of their situations, but sometimes they were not listened to when they talked to them. The ability to challenge professionals to get services or to seek help for their children when needed was an asset that some women brought to the situation. As illustrated in the next comment, some clearly had a hard time dealing with these people:

"I always considered myself to be a private person and I've never been involved with so many people."

Thirdly, having relevant past experiences had an affect on the women's Experience of Enduring. That is, some were inexperienced in all aspects of healthcare. Those women had to grapple with an entirely new phenomena. Whereas, others came into the situation with applicable skills gained from working in a related profession or from their personal backgrounds. They used these skills in such areas as seeking clarification about the child’s specific deficits or for advocating for their children. As illustrated in the next quote, having these skills was a great advantage:

"It's a little bit unique in that I didn't have to learn how to fight, because.. while you are in the middle of the trauma,...I already knew how....I knew what to watch for. "

Finally, each mother's knowledge base about TBI impacted on the initial Experience of Enduring. In the beginning phases, it was hard for all of them to understand the ramifications of their children's TBI. However, those women that came into the situation with previous knowledge about TBI eventually applied that knowledge to their children's situation. Most of the others, who had no knowledge about TBI, were confused about it and its consequences. Although that knowledge was acquired in time, the degree of the confusion
and the length of time it lasted varied between these mothers. One participant's powerful comment exemplifies how some mothers were completely unaware of the ramifications of TBI:

"I didn't know anybody that had a head injury like this....I thought head injury was a goose egg on the head....I never thought it was like this....I never seen these longterm effects....Nothing was like I had seen on TV....Not having the information and never understanding what was going on, and never, never realizing what the longterm effects were."

**Availability of Services**

Access to available services directly affected the mothers' Experience of Enduring. Appropriate services provided the women with help in caregiving, relief from the ongoing responsibilities, and rehabilitation for their children. In situations where appropriate services were obtained, those women valued the assistance. However, a match between available services and their children's condition was required before services were provided. Even when mothers were able to access services, some found the services to be adequate and others found them to be inadequate. In some situations, the women found that services were discontinued once providers realized the full ramifications of their children's TBI. At those times, they experienced frustration and confusion in their attempts to endure the experience and were required to take over as best they could without any help. They commented on the lack of understanding and knowledge about TBI that existed in the service community. The following description vividly portrays the effect of inappropriate services:

"S/he was cutting up her arms,...overdosed on pills and...and even though there were people looking after hi/her,...it obviously wasn't right! So I was in the middle of everything...and because of that I think that people at the rehab facility think they thought I was too interfering...I mean I wasn't there all the time!...When you find out your child has overdosed on pills your...And, and at the very last day they phoned us at 8 in the morning..."Will you come and get your child or s/he"...how did they put it? or "will you come and get your child or shall we have someone come and TAKE HI/HER AWAY! S/he is destroying hi/her room." Well, I..uhh had to drive over and pick hi/her up and, and when things like that happen you got to be there!"
Some expressed their concern that there were no "decent facilities" available for people with TBI. Thus, they had to provide the ongoing caregiving.

In addition, most mothers commented on how there was little help for themselves. These women found that they were on their own. As illustrated in the next comment, some felt abandoned when the healthcare system that had fought so hard to save the child initially, provided no ongoing support:

"I thought there would be more support....I just thought there would be more guidance, I thought there would be more help, I thought there would be more information, that it would come easier, easier to me than having to go out and seek it...I just kind of, I just don't know I just presumed that they saved hi/her that there would be. I didn't think s/he would be so dropped off at the end of the conveyer belt."

**Economic Influences**

Economic Influences impacted on the women having to carry the financial responsibility for the child. Financial responsibility for their children concerned most women. In this regard, the outcomes of the litigation process and the economic influences were intertwined because most looked to that resource to provide for their children. Some could relax somewhat when the settlements provided a "lifetime guarantee" of money for their children. Whereas, others had to seek out alternate sources such as Guaranteed Available Income for Need (GAIN) from the British Columbia government's Income Assistance Division of the Ministry of Social Services, or had to carry most of the financial responsibility. One participant explained her position this way:

"I felt very differently before, because.. but that is a thought that comes to your mind you know...you wonder..Okay, financially now when the courts..the mediation thing went through we thought, "Okay that is one big responsibility off of our shoulders"..knowing where we have been financially in the last four years, because that was a concern you know."
Availability of money also impacted on the ability of mothers to finance services provided by the private sector either for their children or for themselves. When money was available, it allowed the women to have control over services such as respite care or case management. By having this control, they could select the help that they considered satisfactory and in doing so they felt more comfortable about their situations. However, most found that there was not enough money available to finance all the services that were needed such as respite care, support workers, counsellors and in some cases housekeeping help. For example, one woman described how no money was available for her to obtain the grief counselling she sought:

"One of the frustrations for me is that parents need that kind of help [grief counselling] when they need it...I had to pay $95.00 a shot...out of my own pocket which is ridiculous. I mean that is crazy...it should be if the parents are requesting it and they are the primary caregiver of this individual [they should get the help]."

Some women "had to work" and still care for their children. As illustrated in the next comment, others were "thankful" that their husbands were able to provide for the family because that enabled them to stay at home and care for their children:

"He had to get to work and get keep the food on the table...you know, keep the money coming in. And, that has its own stresses and stuff....But, as far as day to day caregiving that fell more on my shoulders...I figured him providing me the means was great! I wasn't going to gripe."

In this section, data were presented to support the Intervening Conditions found in the analysis. Although Mothers' Individual Ways, Availability of Services, and Economic Influences made each situation unique, all were personally effected by the experience. In the next section, these Consequences will be addressed.

**Consequences**

Consequences are the outcomes of Enduring the Experience (Strauss & Corbin, 1990). In this regard, the women experienced both Gains and Losses. In turn, the Gains provided
them with resources to endure the experience, and the Losses made the experience more
difficult to bear. Data supporting these findings will be presented in this section.

Gains

The foremost gain described by mothers was their personal growth. Most
emphasized that undergoing this adversity had been character building. For example, one
participant said:

"It has been an incredible growing experience. We would like to think of growth
happening...uh happening under happy circumstances. But, that is not true. Growth
happens through adversity...and in our life too basically. I think probably more
growth takes place in adversity than through the good times you know. You don't
have to examine things you don't have to change when things are going well. You
know."

Some described how they had become more self-confident and grown into a "stronger", more
forthright, assertive person because of the experience. Those mothers recounted how prior to
the experience they had been shy, avoided conflicts, sat back and took what was meted out at
the expense of their own welfare and that of the child. The following excerpt illustrates this
point:

"You can't sit back....You have to act to do things and before I sat back....I think
its like it has made me stronger...and stand up for myself....I am getting
stronger...feeling that I am right...confident! that is the word yes.. yes and ehh
before I would think "oh well he's a doctor...so he must know better"...or she is a..I
don't know something..But, now I have the confidence to speak up ...to give my
opinion...whatever...so it's so it's yah eh so things happen where you can grow from
them."

Others described how they were already "strong" people but they nevertheless continued to
grow. One woman described her growth this way:

"There has been some major changes - a deepening. I find me as a person, you might
not believe this from this interview, but I find that basically I am a much more quiet
now. I have always been very outgoing...I don't think I have ever been a shallow
person...but there is a very real sense I think..I am a lot deeper today...definitely a
much deeper person."
Increased awareness of the human dilemma around trauma and suffering was also included in most mothers' accounts of personal growth. They related how they had become more compassionate, understanding and sensitive towards others who either had "handicaps" or were experiencing loss or who were going through any type of trauma, particularly TBI. This is exemplified in the comment by one woman who said:

"When I hear about people that uhh you know when there is a car accident or something..somebody has a head injury I am much more affected by it. You know. I just really feel badly for whoever is going to have to deal with whatever is coming up."

Each woman underwent value restructuring which they considered to be part of their growth. Most based their restructuring on the suddenness and unpredictability of the trauma. As a result, they valued the present more than they did previously. Some women found they could no longer make any longterm goals instead they lived for each day. Some found that the experience gave them a different "perspective" about what was important to them. For example, one woman reported:

"I can't waste my time on things that are, in my perspective are really relatively unimportant, you know. There are certain television shows people really like to watch, well that is not my thing anymore. You know I feel life is so precious, that is one of the things that really hit me is the preciousness of life and in a second of time your life can be changed forever which is basically when you talk about change that's what has happened....I think I am a different person, I value life and time."

Others found the restructuring extended into their values about the right to life versus euthanasia. These mothers related how they had changed in that they could understand and would no longer judge people who provided caregiving to persons and then helped them to die. This change in values is evident in one mother's comment:

"It was very hard when you see somebody umm anybody but particularly one of your children not wanting to be alive umm and struggling that hard. I can comprehend..I can absolutely understand people who help their children die....I can understand that. I don't know if it is right or not but I can understand where [it] is coming from you know. So it's uhh uhh that is a little bit different."
The women stated that they had benefited from the learning that came along with the experience. Apart from learning a significant amount of knowledge about the ramifications of TBI which they used in their situations, they also reported that they had benefited from learning in other areas. They described learning about such things as unconditional love, how to manage oneself in situations, their personal limitations and how to work with bureaucracies. The following comment illustrates the learning that occurred:

"I've uh can say on the positive side I have learned an incredible amount of information. Umm I've learned a lot about unconditional love. I would never ever want to see somebody have to go through what we've been through as a family...It was the worst experience in my entire life I can honestly say that, and I wouldn't want to go back there but I have learned a terrific amount."

Another gain described by most women was their change in their approach to their public life. Some found that the experience had broadened their outlook. As a result of this change, these mothers took part in things that ordinarily they would not have done. Most wanted to use their knowledge about TBI to help out the "head injury" community by advocating for it or supporting others who were going through the same experience. Prior to the experience, they would not have taken on this cause. Some found the phenomenon had given them a direction or had channelled them and they thought that was a good thing. For example, one woman said:

"The whole thing has given, has sort of given me sort of another direction for my life in a way, you know. But, that isn't what I would have chosen but...like I mean maybe I didn't have any, um, you know I've always liked to travel and things like that, you know, I didn't have any specific interests, I was just watching."

Also, all mothers found that they had gained through meeting "different people" as well as people who were "unique", "exceptional", "incredible" and "wonderful". An example of meeting wonderful people is found in the following comment:
"If there is anything good in this head injury it was we've met wonderful people. Our paths would never have crossed...I've gained some longer term relationships and friendships...I've really met some kind people, good people."

In turn, these people helped the women to endure. One women described how these "incredible people" gave her comfort:

"We have had comfort expressed to us from people...that have been through trauma of a different nature. And it seems once you have been through that there's a kind of mutual compassionate bond there you know...And, I don't have to have gone through the trauma of someone else...to be able to comfort them you know...but there is definitely a bond when the issues are fairly similar, like when they can mesh one another...But we have met...one of the good sides of this is that we have met incredible people."

Loses

The Losses were found to be profound. Not only did the women endure their children's losses, they also experienced significant losses in their own lives. They articulated that their "lives stopped", their "world was turned upside down" and their dreams had been broken by the ongoing ramifications of the injury. Most found that their expectations about how their lives would have unfolded were shattered. The statement by one mother illustrates the magnitude of the Losses:

"I mean it's totally changed, changed our lives and what expectations we had in our lives... It wasn't the way I thought things would go. I didn't think at my age, think that I would be doing this, you know that my children would have been totally independent and you know there would have been more time for me and my husband to do things together...It was a 360 degree turn in our life, our lifestyle and what we our expectations were out of life....I guess you always kind of think as a parent well, when I grow old and you know, my kids will help look after me or whatever, umm, you know. I have the sense of being cheated out of all that."

The broken dream component for some women was partly influenced by loss of freedom resulting from the ongoing caregiving. As illustrated in the following comment, the loss of freedom infringed on their dreams about doing such things as being able to travel at "this stage in life":

"
"Obviously now my youngest is nineteen and my husband is at the age where he could be retiring and uhh that is not an option for us, you know. We can't couldn't be travelling extensively because I haven't got a network in place YET that works properly. S/he is very dependent on us."

This loss of freedom had a domino affect for these women. They experienced a loss of spontaneity when they were required to preplan around their children's schedule and substitute caregiver's schedules. For example, one woman said:

"I guess one of the things I feel like I can't, I can't make any spontaneous plans, you know, like I have to, I guess I miss that, being able to come and go...I have become a real scrooge about time...like...the support workers if they're late, I'm just, you know really frowning...[that their lateness has] infringed on my precious few hours or minutes."

They also experienced a loss of doing things that they had enjoyed prior to their children's TBI. The following excerpt illustrates this point:

"I don't have the chance to go out whenever I want. I don't have the luxury to sleep in anymore or just go shopping today....Everything takes a lot of preplanning..you just can't...do things..you've got to watch your schedule have... bowel care done...have tube feeds done...you just can't plan a vacation and go away...Its always there...Its not like I am going to do this today, its not that way....Haven't had a holiday in nine years...we've taken hi/her."

Furthermore, loss of freedom was partly responsible for some mothers' career losses. That is, although all participants described significant changes to their job status by either taking part-time jobs or jobs with less responsibilities or quitting their jobs altogether, not all attributed this change solely to loss of freedom. Instead, some found that the demands of the caregiving contributed to these career losses as well. That is, the women reported feeling "exhausted", "burned out", "constantly stretched", and "emotionally and totally spent". They emphasized that this phenomena was not entirely due to the caregiving, but that they became "overloaded" when the caregiving was added to their everyday demands. As a result, mothers who did have the freedom to pursue and/or advance in their careers had "no stamina" and "no energy left" to do so. Loss of career resulted in financial loss for some
mothers as well as other losses. As exemplified in the following comment, career losses also had a domino effect:

"I have a great sense of loss....I lost my job, I lost my friends...I have a hole in my heart....Not only the loss of a child,...I've lost my career...lost friendships I had with friends and colleagues...a big domino effect."

Some women experienced losses such as loss of privacy, loss of personal space and loss of a sense of security. Personal space losses were attributed to the child always being present, and security losses resulted from the unpredictability in the child. Others disclosed that they had a loss of "feeling carefree as before" because of the experience. The impact of the loss of a sense of security is explained by one mother who said:

"For many years you lose your sense of security I guess. You know. Its like you can't be sure what you are going to be doing tomorrow or next week or ...It's a loss of a sense of security, I don't know what's happening tomorrow."

All mothers underwent a loss of trust in a system or systems after having a negative incident. Generally, this distrust developed after the women had willingly accepted the advice or help provided by the system and then found it to be unreliable and even harmful. They only mistrusted those systems in which those experiences had occurred. The loss of trust could occur at any time, such as at the onset or well into the post-injury phase. In each case, once the trust was lost, it did not get restored. At the same time, the women respected and revered those systems in which they had had a good experience. Systems included the medical profession, the healthcare system, service providers, the insurance corporation, brain injury societies, and the legal system. This next comment illustrates how one mother lost trust in the legal system:

"We already had a court case and lost and now we are appealing. The whole court experience is horrendous. It's an eye opener! It's a big business, a game. There is only one answer. Experts say things depending on what side they are on. I am cynical about the whole justice system. It's expensive. I have mortgaged my house
to pay legal bills. Our lawyer has us on a contingency but there are still expenses to cover."

The women perceived a loss of living a conventional, "normal" life. Most found the experience to be lonely because they were "different" from others in society. Some "wished" that they could one day live a "normal life". The following quote from one woman reveals the loneliness of the experience:

"You know until I think you have walked that path you cannot possibly understand the impact that it has."

Although all of the aforementioned losses were significant contributors to mothers' Experience of Enduring, most described their children's losses as being the predominate loss. A mother described the significance of that loss this way:

"I think one of the major issues for me as a mom has been the issue around loss. Loss of who s/he was as a person. S/he was just so self confident and vital and alive and popular you name it. S/he had all the positive things happening for hi/her in hi/her life. But loss of umm definitely who s/he was...loss of the future and the potential that s/he had...I mean every parent has hope for their kids...S/he had literally the world at hi/her fingertips."

Most women experienced ongoing grieving as a result of their children's losses. They described how they could not put closure to their loss because "it's always there". Some described that losing "a child in this way" produced such intense and deep feelings of grief that it could not be compared to any other loss that they had endured. One participant's description vividly portrays the impact of her child's losses:

"I think that is a very big term you know [broken dreams] and... and that... that I think is one of the biggest part of the grief load that a parent carries is that... that broken dream thing their broken dreams for the child their child's broken dream. Like my child wanted to be a pilot...and as a result of her TBI s/he was never able to fly again. Altitude changes just whack hi/her whole sense of balance out s/he loses horizon...so that was it, that was over...I think that is one of the biggest factors in the grief component you know and a child dies that is the end of the hopes and dreams and you can grieve and get on with it but when you have to see them everyday struggling with their life with their hopes and dreams that's a big component you know. That...that one keeps the wound open a long time."
In this section, the Consequences found in the data analysis have been illustrated by representative data. Excerpts to support both the Gains and Losses have been presented.

Summary

This chapter has described the results of the analysis of the data that illustrate mothers' experiences of being primary caregivers to their previously independent adult children when they sustained TBI. The findings indicate that The Experience was one of Enduring at three levels: Becoming a Caregiver, Grasping Reality, and Carrying Responsibility. To endure, the women used tactics that included Pulling from Within, Comparing in Order to Put a Face On It, and Dealing With It. Individual sets of circumstances influenced each mother's Experience of Enduring, such as the Mothers' Individual Ways, Availability of Services and Economic Influences. As a consequence of The Experience of Enduring, the women realized both Gains and Losses in their lives. In turn, these consequences either helped them to endure and survive the situation or were a source of suffering for them. Each mother's Experience of Enduring was unique and dependent upon the individual aspects and attributes of the caregiving, the reality, the responsibility, the tactics used, the sets of circumstances, and the consequences.
CHAPTER FIVE
Discussion

Chapter four presented the outcome of the constant comparative method of data analysis, as outlined in Strauss and Corbin (1990), of mothers' collective descriptions of their experiences of becoming primary caregivers to their previously independent adult children who had sustained TBI. In this chapter, the research findings are discussed in relation to the literature. To begin this discussion, Ryan's work will be revisited and compared to the findings of this study. Then, the discussion will be guided by the categories and subcategories of The Experience of Enduring framework with only pertinent points being addressed.

**Relationship of Findings to Ryan's (1993) Study**

Ryan's work was used to start this study because at that time it was the only one available that addressed mothers as caregivers to their adult children. It provided a worthwhile and needed base for the literature review and data collection phases. However, in order to comply with the inductive process of qualitative studies, it was set aside at the data analysis phase and the constant comparative method of data analysis as outlined in Strauss and Corbin (1990) was used. At this point, the similarities and differences between the findings of the two studies will be discussed.

Firstly, several similarities between the two groups of mothers were found within the mothering caregiving role. That is, the role was taken on because of their adult children's inability to function independently. Although in Ryan, the role was taken on for an indefinite period of time because the child could not function independently. And, in this study, the mothers returned to a previously held active mothering role because the child no longer functioned independently. The caregiving was: complex because their adult children did not
attain adult independence or were no longer like adults; difficult because of their children's vulnerability; and onerous, constant, all-encompassing and central to their lives. In addition, both groups managed the caregiving by going day-to-day. Even though other family members were present, both groups carried the full responsibility for caregiving that they found to be interminable. The caregiving activities that were found to be similar included: accommodating to their children's needs; protecting; advocating; and being highly involved in their children's day-to-day life. Also, being flexible was a caregiving tactic used by mothers when managing unpredictable behavior, but, not all of the participants in this study experienced unpredictable behavior in their children.

Secondly, both sets of mothers had similar experiences with the community and the health care system; that is, lack of support for themselves and lack of understanding about their children's condition. As well, stigma was an issue for all in Ryan's study and for some in this study. In addition, all mothers in Ryan's study and most of the mothers in this study found the health care services to be inadequate. Reactions were similar when inappropriate help was provided for the child. Finally, the way that the situation impacted on personal lives was comparable. That is, both groups experienced: loss of the adult to adult relationship with the child; loss of expectations for what might have been for the child; chronic sorrow; and dealing with feelings of being "alone" in their experience. And, both recognized the need to take care of themselves and sought out ways to do so. Furthermore, loss of freedom was experienced by all in Ryan's study and most in this study.

The major differences between the experiences of mothers in Ryan's study and the mothers in this study stem from the difference between the chronic illness trajectory of schizophrenia and the permanent disability caused by a TBI. Schizophrenia is a major mental illness that has an unpredictable course of exacerbations and remissions (Ryan, 1993). Its
symptomatology of delusions, emotional lability and hallucination, although difficult to manage, can often be controlled with drug therapy. The ongoing research about the illness and the advancements in drug therapies has resulted in the knowledge and treatment of the disorder constantly moving forward and providing those affected by the illness with hope. Whereas, TBI results in a diverse and dramatic range of permanent disabilities in those affected. It cannot be treated.

In regards to differences between the two groups, aspects regarding the mothers' descriptions of their children's level of functioning were found to be dissimilar. Ryan's participants used the term a "young child", whereas, in the present study, mothers' descriptions ranged from being an infant or a baby to a teen-ager or a much younger person. In addition, how the mothers perceived the changes in their children's level of functioning differed. In Ryan's group, the changes were attributed to the illness trajectory of schizophrenia, whereas in this study changes were attributed to the "changed child". Although the mothers in the present study recognized that the TBI caused the changes in their children, the injury was considered as part of their children and was not viewed as a separate entity. This difference was evident in the areas of acceptance, uncertainty, and hope. For example, acceptance, for Ryan's women, included acceptance of the illness and the child's limitations that resulted from that illness, whereas in this study, the participants worked at accepting the trauma and the "new child". And, although both groups had uncertainty about the future and were concerned about what would happen to their children when they were no longer able to provide care, the reasons for those concerns differed. In the present study, participants' concerns were based on whether their changed children would have access to the needed ongoing support and caregiving. Whereas, in Ryan's group, the uncertainty and concerns stemmed from the uncertainty of the illness trajectory. Paradoxically, that
uncertainty gave those mothers hope that their children's condition might improve over time. Whereas, the women in this study had no hopes for great improvements in their changed children, instead, they were resigned that their children would be permanently disabled, and viewed their children as a "new child". They lived with their children's concrete changes and permanent loss of potential. They had no expectations for age appropriate behavior or goals, even though some tried to encourage appropriate behavior.

The mothers in this study attitudes about the permanent loss of their children's potential were unlike Ryan's participants who referred to their children as having undergone regression. They believed that their children's growth had been interrupted because of the illness symptomatology. As a result, they continued on with their attempts to normalize their children's behavior by encouraging and expecting age appropriate behaviors. They held out hope that their children would one day be able to attain economic and social independence and emotional maturity.

Ryan's participants' beliefs that the chronic illness had caused an interruption was evident in that portion of the disruption construct relating to the mothers' lives. That is, the mothers considered their lives as being "interrupted" as they lived with the day-to-day disorder in their lives. This perspective differed considerably to the women in this study who were found to be "Enduring The Experience" of the permanent change in the order of their lives.

In the above discussion, the apparent similarities and differences between the experiences of mothers in this study and those in Ryan's study were presented. In the next section, the discussion will return to the findings of the analysis of this current study and the findings will be discussed in relation to the literature.
The Experience of Enduring

The following discussion will be guided by categories that make up The Experience of Enduring framework. To begin this section, the core category The Experience of Enduring will be addressed in relation to the literature.

The findings of this study identified the core category The Experience of Enduring as the central phenomena to which all the other categories were systematically related. It was "enduring" that captured the essence of the mothers' experiences of the ongoing caregiving and their persistence and perseverance as they remained steadfast in their commitment to care give and to continue on with their endless responsibility. Enduring also elucidates the heartaches that they suffered over the realities of the experience. Accordingly, enduring, in this current study, underscores how the mothers undergo a lasting caregiving experience.

The nursing research on enduring does not speak to this phenomena as clearly as the social science and medical literature. Albeit, in one nursing study, families of young children with developmental disabilities are referred to as "enduring the hardships" brought about by the disability (Villarreal & Johnson, 1995, p. 96). Nonetheless, it is in the social science literature that enduring is used to describe: the lasting bond in families (Hashimoto, 1993) and in friendships (MacRae, 1996); the lasting attachments that mothers have to their children (as described in Chapter 2) (Bowlby, 1988); and the ongoing suffering that survivors of significant others who were murdered experience (Sprang, McNeil & Wright, 1989). And, in the medical and mental health literature, enduring is the term used to describe the persisting effects of major mental illness (Coryell et al., 1993; Gournay, 1995). Thus, enduring as it is used in this current study corresponds to the depiction of enduring in the above literature.
In this current study, enduring depicts the ongoing experience of the TBI caregiving mothers. Whereas, in nursing studies, because enduring is so often studied in terms of a disease/illness, it is something that is gone through and is not an end point, nor is it to be lasting (Knafl, Breitmeyer, Gallo, & Zoeller, 1996; Howard, 1994; Huckstadt, 1990; Lindgren, 1993; Morse & Carter, 1995, 1996; Morse & O'Brien, 1995; Wilson & Morse, 1991). For example, Howard and Lindgren depict enduring as a middle stage of the caregiving process. And, in Knafl et al., enduring describes one family management style used by families when managing childhood chronic illness, and when the enduring style is used families do not to realize normalization, the goal of adapting to chronic illness. In Wilson and Morse, enduring is considered one aspect of the middle stage of the buffering process used by husbands when living with wives undergoing chemotherapy. Also, Huckstadt noted that elderly patients in hospital engaged in a process of enduring so that they could go home. As well, in Morse and O'Brien, 'enduring the self' was identified as a middle stage of a four stage process that explained the strategies used by survivors of life threatening accidents who were transformed into disabled persons. And, in Morse and Carter (1995, 1996), enduring is a state that is moved through to suffering when the individual is emotionally strong enough to experience the onslaught of the illness. Furthermore, in Dow's (1990) theoretical paper, she likened the cancer experience to 'enduring the seasons of survival' that had to be moved through otherwise thriving would not occur. Hence, the essence of the above literature is that is "enduring" is not considered to be a permanent state. Whereas in this present study, the findings revealed that Enduring explained the caregiving experience that was ongoing and necessary.

Nevertheless, some of the attributes that the above authors have ascribed to 'enduring' correspond to the findings of this present study. That is, the mothers in this present study
enduring the process of Becoming a Caregiver to their adult children when they sustained TBI is similar to Howard's (1994) enduring stage as described in detail in Chapter 2. When in the enduring stage, caregiving mothers learning to live with their children who developed schizophrenia demonstrated persistence and perseverance to provide the caregiving without having an understanding of the illness nor having meaningful support. But, as they continued on in the caregiving they also worked at gleaning an understanding of the illness and finding meaningful support. Thus, the findings of this study that it took time for the mothers before they understood the full ramifications of their children's TBI, and yet they persevered and persisted to continue the caregiving, and most doing so without meaningful support, corresponds to Howard's enduring stage.

Furthermore, the mothers in this present study enduring the process of Carrying Responsibility, getting help to endure by using tactics, and experiencing the consequences of enduring is analogous to several attributes of the enduring stage described by Lindgren (1993). The similarities include: (1) heavy caregiving workloads including controlling disruptive behavior; (2) seeking pertinent caregiving information; (3) meeting the duties required of running the home; (4) looking for relief from tasks; (5) taking a day-to-day attitude about life; and (6) personal disruptions such as social isolation, loss of reciprocity, feeling hopeless about the situation. Thus, the findings of this present study that mothers are enduring the heavy caregiving demands and the changes to their lifespan expectations, and yet they develop and use tactics that help them to endure reflect Lindgren's enduring stage. Furthermore, mothers in this study were enduring the process of Grasping Reality. In Lindgren, when caregivers are in the enduring stage, they have knowledge of the illness and have adjusted to the caregiving role. Therefore, the findings of this current study that mothers endure the process of realizing the ramifications of their children's TBI also
corresponds to Lindgren's enduring stage. Additionally, in this current study, the process of Carrying Responsibility was linked to mothers finding appropriate placements. In Lindgren, caregivers struggled to make the decisions to place their care recipient in nursing homes (As described in Chapter 2). The findings of this present study that mothers would place their children in a facility if they could find an acceptable placement differs with that aspect of Lindgren's enduring stage.

In this study, enduring the processes of Becoming a Caregiver, Carrying Responsibility and Grasping Reality are comparable to some of Knafl et al.'s (1996) depiction of the "enduring" family management style. That style included: families being proactive and protective; the illness experience defined as being difficult, overwhelming and "ever present"; the young child seen as a tragic figure whose life chances had been "irreparably compromised as a result of the illness" (p. 320); families constructing their lives as being not 'normal'; and some dreading the future. The findings of this present study that correspond with Knafl et al.'s include: the caregiving being all encompassing and challenging; the caregiving strategy of being protective; seeking services when "dealing with it"; the loss of the former children; mothers constructing their lives as not being "normal"; and mothers' concerns for the future. However, Knafl et al.'s enduring style also included families sheltering the child instead of encouraging the usual childhood activities, and that style is not reflected in the findings of this study. As well, other areas in Knafl et al.'s research that differ from the findings in this present study include families feeling confident they could manage the illness, their focusing on the huge effort to do so, and their describing that effort as a "burden". One area that cannot be commented on is Knafl et al. noting that the illness experiences had negative consequences for family life. Noting what the consequences of TBI caregiving had on family life was beyond the scope of this study.
In addition, using Inside Work to hold their families together when enduring is comparable to Wilson and Morse's (1991) depiction of enduring. That is, when enduring, husbands watched the toll that chemotherapy had on their wives and family and struggled to buffer their wives from extra stress or pain. Although they too suffered, they took care to conceal their suffering. Enduring for them was working at not being depressed or "overwhelmed with sadness" and "being strong" for the family (p. 83). That mothers' Inside Work included protecting their families from the ramifications of the TBI by taking on all of the caregiving responsibility and encouraging family members to move on compares with the findings of Wilson and Morse.

Aspects of the Grasping Reality compare with Morse and O'Brien's (1995) enduring stage. That is, in Morse and O'Brien, when survivors of trauma were in the enduring stage, they started the psychological healing process by confronting the reality of their accidents and the meaning of their irrevocable losses, and by regrouping by coming to terms with those realities. That when mothers were Grasping Reality, they came to terms with the trauma, their changed children, and their caregiving situations parallels Morse and O'Brien's enduring stage.

Other literature that speaks to the Grasping Reality process identified in this present study is Dow's (1990) theory. Dow theorized that enduring was required by cancer patients to handle the fear of recurrence and the unknown, and to adjust to disabilities and radical life changes. That mothers, in this study, endured the fear of the future and strove to accept their changed children and the changes in their lives corresponds with Dow.

In this study, mothers gained strength to endure by Pulling from Within and from the support from understanding people is comparable to the research of Huckstadt (1990). She found that the hospitalized elderly process of enduring required energy that had to be
balanced by energy received. The energy came from the elderly's "self determination" and the support from professionals, volunteers, friends and families.

In the findings of this study, mothers demonstrated that they were enduring extremely difficult situations. The research of Morse and Carter (1995, 1996) addresses enduring as it is found in the illness experience. According to them enduring is "the capacity to last, to get through, to survive an experience or an intolerable situation" (1995, p. 39). The essential characteristic of the capacity of enduring is the 'holding on' response, to last through it. In this study, the experience was enduring and that does not entirely reflect Morse and Carters' definition because the mothers did not get through it, that is, the caregiving was ongoing. However, what is pertinent to this study is that the participants did demonstrate the capacity to last and hold on.

This section presented a discussion of the core category The Experience of Enduring in relation to the literature addressing enduring. Several aspects of the concept enduring described in the literature were found to be similar to the findings of this study. In the next sections, pertinent points of Becoming a Caregiver, Grasping Reality and Carrying Responsibility will be discussed in relation to the literature.

**Becoming a Caregiver**

The women in this study made conscious decisions to become caregivers. They responded to their children's needs for caregiving and were concerned about their children's welfare if they did not do it. In the literature, attachment theory, that was described in Chapter 2, explains why the women took on the caregiving role (Bowlby, 1982). That is, the findings of this present study indicated that it was attachment that seemed to motivate the mothers.
The mothers in this current study had to learn about their "new" adult children and how to provide care to them. The process of learning about their TBI children and how to be a caregiver to their changed adult children corresponds to Sullivan's (1989) work that addressed the thinking and decision making of mothers of new babies. In Sullivan, the mothers underwent a process of "learning the baby" and that included "trying to figure out" the baby's needs by observing, questioning and listening to the baby (p. 59). Learning the baby was ongoing because of their children's growth and development. The findings of this study that the mothers had to learn their "new" adult children and how to provide care that would meet their children's needs that changed over time, albeit the changes were minimal, reflects Sullivan's research.

The women in this study did not experience an ongoing independent development in their children, instead, their children's independent development was insignificant and that made letting go complex. In Sullivan (1989), the process of "letting go" was used by the mothers as they "let go" helping their children in those areas that their children succeeded in functioning independently. Because their children continuously developed, the mothers constantly looked for and welcomed signs of independence. The findings of this present study that the adult children did not continuously develop their independence does not correspond with Sullivan's work. Thus, the mothers in this present study are unable to "let go" because their children cannot function independently.

The caregiving strategies used by the women in this present study were influenced by their children's inability to function independently. They focused their energies on enduring the process of Becoming a Caregiver and that included learning how to give the most appropriate care to their children. In Carson's (1993) study, independence was also found to be a paramount issue for the parents of previously independent adult children who had
sustained a TBI. Carson's study is described in Chapter 2. Carson found that the parents took on the caregiving role because they were "investing in the comeback" of their children's independence (p. 167). She found that during the first stage of investing in the comeback, they fashioned their caregiving with the belief that their pre-injury child could be contacted if they used the right approach and as they gave care, they looked for the "essential person" (p. 167). The findings in this present study that the mothers focused on learning how to care give their children does not reflect Carson's "investing in the comeback stage", that is, it was not apparent that the mothers had ever held the belief that the pre-injury child existed. Nevertheless, in both studies, participants were focused on taking actions that would expedite their children's optimal functioning. And, the caregiving activities that were assumed were dependent on their children's level of functioning that was constantly changing. In this study, the change in most of the children's level of functioning was very minimal.

Several caregiving tasks identified in this present study are comparable to those identified in Carson (1993). In particular, both sets of participants reported that initially they were providing most if not all of their children's "physical daily living tasks" (p. 168). Having to provide that type of care diminished over time for both. The mothers in this study attributed the lessening of the physical caregiving to the improvements in their children's physical functioning. Whereas, Carson attributed the diminishing of having to provide physical care to the caregivers becoming more proficient in their ability to perform physical caregiving tasks. Thus, because the caregivers could do the tasks quicker, the physical caregiving became easier for them. Also, both sets of participants had to advocate for services for their children. As well, both had to "acquire new parenting skills" (p. 168). However, Carson noted that the parenting skills reported were activities such as going to doctors appointments or doing paper work, whereas in this study, the skills described by the
mothers were direct parenting skills such as rule making. In addition, both protected their children. Although in Carson's study, because protection was based on their children's physical deficits, the parents strove to provide a safe physical environment. Whereas, in this study, mothers were protecting their children because of their vulnerability related to their physical deficits as well as their behavior. Restructuring the physical environment was identified as a caregiving factor in Carson, but in this study the mothers did not directly comment on that area.

In addition, the experiences of some of the women in this present study correspond to those reported by Carson (1993) during the second stage of "Investing in the Comeback" that focused on transferring independence back to their children (p. 170). It is significant to note that in this study, some of the mothers were not faced with having to handle the independence as described by Carson, because their children could never function independently. However, those that were dealing with those issues had similar concerns and used comparable caregiving strategies identified in Carson. That is, in both studies, participants found that the strategies to promote independence were cultivated through trial and error because there were no reference books available that addressed their children's unique injury nor their recovery. Similar caregiving strategies were identified and included: finding a balance between wanting to protect the children and wanting the children to function independently; supporting the children and "limiting rescue"; encouraging the children to make decisions and then accepting those decisions without rushing in to take over; and setting limits on the children's behavior. In this study, the women only set limits when they perceived that their children were ready to make changes in their behavior. Whereas in Carson (1993), the parents enforced the standards of what constituted allowable behavior because they had adopted preferential rules during the initial stage of recovery.
The mothers in this present study found that when the physical care was no longer required, they still had heavy caregiving demands which were all encompassing, difficult and challenging. Conversely, Carson (1993) placed an emphasis on the demands of physical caregiving. She stated that initially the caregiving was all encompassing and later less encompassing. Although she did find that the mothers continued to keep their "brain-injured" children as a primary focus. The findings of this present study that even though the physical demands of caregiving lessened the caregiving was still extremely difficult does not reflect Carson's conclusions.

Most of the participants in this study functioned as coordinators of all aspects of their children's lives. Although the TBI literature does not address that particular finding, it is reported that mothers act as case managers for their children's rehabilitation (Solomon & Sherzer, 1991). And, in the gerontology literature, the caregiving activities of anticipating all of the care recipient's needs; making decisions about what is needed to meet those needs; and then assuming the activities to meet those needs are reported (Bowers, 1987).

In this study, standing by was the caregiving strategy used by most of the mothers to handle their children's social isolation. This finding differs from the results of Kozloff's (1987) study on social isolation in persons with TBI. That is, he found that mothers provided the social interactions and assumed the responsibility for social networking for their adult children.

Grasping Reality

The participants' reality was that the sudden traumatic event had forever changed their lives. However, it took a while before the mothers recognized and accepted the full implications of the TBI. This finding is similar to Lezak's (1986) observation that at the initial stage, families of persons with TBI are absorbed in the caregiving with the expectation
for a full recovery and it takes a while to acknowledge the changes. She also noted that the awareness of the complete change in the survivor is a gradual process that takes place in a series of stages. Several authors have proposed that families do not immediately comprehend the full ramifications of the TBI as related to denial (Leaf, 1993; Ridley, 1989; Rosenthal & Young, 1988), seeing denial as a protective mechanism in the face of a reality too painful to grasp.

Furthermore, it is worth noting the similarities of Grasping Reality to the "confronting reality" phase identified in the cancer literature (Hull, 1989). In Hull, even though primary caregivers of the dying family members knew that the cancer was terminal and that death was inevitable, they did not confront that reality until they were faced with concrete evidence that death was imminent. Similarly, in this study, even though the women knew that their children had a TBI, it took time and concrete evidence and experience to embrace that reality.

The mothers' recognizing that their children were permanently changed and then accepting that reality was part of the process of Grasping Reality. This process was accomplished by viewing their children as "new" or different persons. Similarly, Lezak (1986) reported that eventually families gave up hope and accepted the fact that their members' premorbid personality would never return, they then regarded their members as different persons. A slightly different perspective was reported in Willer, Allen et al. (1990). They noted that after a while the mothers accepted their sons' limitations and abandoned many previous hopes. Willer, Allen et al. make no reference to the mothers viewing their sons as different persons.

When the mothers grasped the reality of their children's permanent change, they also had to come to terms with how those changes would impact on their lives and that caused the
mothers concern. A comparable finding was noted in Carson (1993). She found that once parents realized that their adult children would never be independent, they also realized that their children would be a permanent part of their household and that caused the parents deep concern. Whereas, Lezak (1986) and Willer, Allen et al. (1990) reported that accepting the reality of the permanent change in their family member was a positive experience. That is, Lezak noted that families got emotional freedom that allowed them to take on activities other than caring for their member. And, Willer, Allen et al. reported that mothers found the acceptance to be a coping mechanism.

In addition, coming to terms with the trauma was another aspect of Grasping Reality for the women in this study. The participants had strong responses to the traumatic event that included: vividly, emotionally and extensively describing the whole scenario around the accident; having an intense fear of losing another child when thinking about it; feeling different from others in society; and being engulfed by feelings associated with the accident. These experiences of coming to terms with the traumatic event compares with aspects of the post traumatic stress disorder (PTSD) literature. In Norman (1989), PTSD is defined as a "psychological reaction to a[n] overwhelming stressful event that is beyond expected daily incidents" occurring well after that event has passed, and it can be prolonged (p. 55). The symptoms of PTSD include: reexperiencing the event "in painful recollections", dreams or nightmares; experiencing a "loss of emotional response to the world around"; feeling alienated and detached from the external world; experiencing painful emotions such as feeling guilty or sad; and hypervigilance (p. 55). Furthermore, these emotional responses exert "a degree of control over everyday life" (p. 55). These symptoms correspond to the experiences of the mothers in this study.
In this study, it was found that the mothers were enduring while going through the process of Grasping Reality and the other two processes as well. A somewhat different way of viewing Grasping Reality is found in Morse and Carter's (1995, 1996) description of "suffering". In the context of their work, suffering is the "emotional response to enduring" and it is during suffering that one acknowledges what has happened, "piece reality together" and accept the losses. In Morse and Carter's views, suffering occurs following the enduring phase. In contrast, in this study, Grasping Reality is just one piece of the process of enduring.

**Carrying Responsibility**

The women in this study carried the ongoing responsibility for their previously independent adult children who now functioned at a considerably younger age level and who had permanent disabilities. Being committed to Carrying Responsibility and being there for their children is the essence of maternal thinking described in attachment theory (Bowlby, 1988). (As described in Chapter 2.). The findings of this study supports the theory.

The findings of this present study that mothers carried the responsibility because they felt responsible corresponds to the processes "embracing responsibility" and "being there" identified in Sullivan's (1989) research that addressed maternal thinking. Embracing responsibility is described as the selfless giving to children and "doing the right thing" for them (p. 85). Sullivan found that when embracing responsibility, mothers safeguarded their children from harm and they made urgent responses when anything threatened their children's survival. Similarly, in this study, even though mothers would have liked to be free from carrying the responsibility they remained committed to being responsible for their children because they were concerned about their survival. They would not relinquish the responsibility unless their children were in situations that they considered suitable. The
mothers intrinsic enduring sense of feeling responsible for their "new" children's survival and safety parallels Sullivan's process of "being there". Sullivan noted that being there happened when the mothers of new babies accepted "the responsibility of caring for their babies as the new priority in their lives" (p. 50). The mothers recognized that their babies needed them to survive and the survival of their babies took precedence in their lives. The mothers projected that they would be available throughout their children's lives if the child needed them. Sullivan noted that "being there" is a lifelong commitment to protect, to care for, to cherish and to "provide direction for the baby/child/adult" (p. 50). Similarly, in this study, the mothers felt committed to being responsible for caregiving and understood that their "new" children would not survive if they did not take on that responsibility.

The findings of this study suggested that mothers feelings of responsibility for their children mitigated their caregiver burden. A similar finding was noted in Boland and Sim's (1996) study that addressed the caregiving experience. Although responsibility is often considered synonymous with burden, they found that when the commitment to care was expressed as a personal responsibility, then that feeling of responsibility seemed to moderate the caregiving burden.

That burden did not emerge as a theme in this current study parallels the findings of Perry (1996). She found that wives caring for their elderly husbands with Alzheimer's disease organized the caregiving around "caring" as a theme and this seemed to allay burden. That is, the relationship with their husbands and the "family orientation" was important to the wives and seemed to be more powerful than focusing on burden. Perry suggested that burden is not "a powerful enough construct to emerge over variables such as structure, commitment, beliefs and values" (p. 117). The findings of this current study that mothers were committed
and cared about the welfare of their children and that seemed to override their focusing on burden compares with Perry's study.

**Tactics Used by Mothers**

The mothers in this study endured their caregiving responsibilities and used the tactics that they deemed necessary. Some helped them to endure and others made the experience more difficult. Evidence can be found in the literature to support this finding.

**Pulling From Within**

The tactic Pulling from Within gave the women in this study strength to endure. One aspect of this tactic was the affectionate past relationship that the women had with their changed children. The importance that past relationships have on influencing the caregiving experience is reported mainly in literature that addresses caregivers of the elderly (Cartwright, Archbold, Stewart, & Limandri, 1994; Horowitz & Shindelman 1983; Langner, 1993; Neufeld & Harrison, 1995; Nkongho & Archbold, 1995). Affection and reciprocity have been two of the main relational aspects studied (Horowitz & Shindelman; Nkongho & Archbold). In Horowitz and Shindelman's study, they reported that an absence of affection did not deter families from caregiving, but greater "disruption and distress" was perceived by caregivers (p. 19). However, they found a positive correlation between affection and level of commitment, and a negative correlation between affection and the "level of caregiving impact" (ie. Caregiver impact is considered to be synonymous with caregiver burden.) (p. 18). Reciprocity is irrelevant to the mothers in this current study.

Some participants in this study getting strength to endure by pulling from their spiritual beliefs compares with Mauss-Clum and Ryan's (1981) findings. They reported that caregivers used prayer as a coping mechanism.
Comparing in Order to Put a Face On It

The tactic of Comparing in Order to Put a Face On It was used by the mothers in this present study as a way to validate the experience. One use of comparing was to delineate the caregiving situation. No literature was found that addressed using comparison in this way, therefore social psychology theory was drawn upon. According to social psychology theory, people use social comparisons to evaluate their skills and abilities when "objective indicators are lacking" (Affleck & Tennon, 1991, p. 369). Lack of objective indicators for the TBI phenomena is well recognized. That is, because TBI is a recent phenomenon, researchers have emphasized that the specific burdens that primary caregivers of persons with TBI experience are still being identified (Chwalisz, 1992; Gervasio & Kreutzer, 1997; Livingston & Brooks, 1988). Hence, to make sense of their situations, primary caregivers have no reference points specific to TBI that can be used. In this current study, the findings indicated that by making social comparisons the mothers were able to establish that their caregiving situations were difficult. Establishing the difficulty was accomplished by the women comparing their situations to other situations in which the degree of difficulty was readily recognized. By using social comparisons in this way, the mothers were able to validate that they were enduring these tremendously difficult situations.

Dealing With It

Inside Work. The women in this present study used tactics to hold themselves and their families together and by doing so that helped them to endure their situations.

One tactic used by the mothers was doing activities which helped them to endure. A similar finding was reported by Hull’s (1989) study. Hull found that the caregivers most successful means of dealing with the strains associated with caregiving responsibilities was creating "windows of time" away from the role in order to pursue activities that were
meaningful to them (p. 158). The caregivers were able to access several respite services to do so. Even though in this present study most of the women found that respite services were limited they still did try to take care of themselves.

Mothers in this study seeking out support from understanding people and taking part in recreational activities as a means to take care of themselves compares with Mauss-Clum and Ryan's (1981) findings. They noted that caregivers identified the coping strategies attending support groups, talking with friends, and taking part in recreation.

A goal of the participants this study was to protect the rest of the family from the ramifications of the TBI. They encouraged their family members to move on, took full responsibility for caregiving, and strived to provide a "normal" family life. That differs from the reports of Carson (1993) and Brown and McCormick (1988). Carson found that parents placed the highest priority on meeting the needs and wants of the injured child and their other children's needs were secondary. And, Brown and McCormick reported that other family members felt neglected, yet the caregivers believed that the member with the TBI needed them, therefore, the other family members should understand. The findings of this study that mothers worked to hold the family together is not congruent with those of Carson and Brown and McCormick.

Outside Work. Although several aspects of Outside Work were identified in this study, only two aspects will be presented. First, the mothers in this study encountered a lack of knowledge of TBI in our society that often manifested itself as stigma. No studies were found that addressed the issue of stigma of TBI and the impact that this stigma has on the family. Lack of research in this area was underscored by Ridley (1989) who contended that persons with TBI are subject to the greatest degree of stigma of any other group. That is, Ridley noted that in our culture a broad range of disabilities carry stigma and a hierarchy of
stigma exists with conditions entailing loss of rationality and control along with mental illness being regarded least favourably. She emphasized that "in the ideology of the modern age" a high value is placed on predictability, rational and controlled behavior (p. 556). As a result, a person with TBI manifesting "cognitive impairments, [and] subject to episodes of uninhibited behavior, threatens these values more than a person with any other kind of disability" (p. 557).

Another aspect of Outside Work was litigation. Each participant in this current study considered the work of litigation or arbitration to be an enormous responsibility that often ended in disappointment. The disappointment was partly based on judgements being made about their children's future when there was so much uncertainty about TBI and how the TBI would impact on their children's lives. No literature was found that addressed the issue of mothers going through litigation or arbitrating on behalf of their children with TBI. Considering the impact that the work of litigation had on these mothers' lives it is surprising that this issue has not been addressed.

Intervening Conditions

The findings in this present study demonstrated that each caregiving situation was unique and the intervening conditions contributed to the uniqueness.

Mothers' Individual Ways

The various abilities the women in this present study brought to their caregiving situations was identified as one individual way that impacted on the initial caregiving experience. Those that brought to the TBI experience an understanding of the health care system had little expectations from it, and as a result they challenged professionals and tried to work things out in order to get what was needed for their children. They came into the TBI experience prepared to take charge. Others who lacked experience in working with the
health care system felt disappointed and frustrated when they did not get the care that they
had expected would be provided. In the literature, the experience of working with the
system, recognizing its limitations, and realizing that one has to take charge to get the needed
services fits with Thorne's (1993) description of "guarded alliance". According to Thorne,
guarded alliance is the result of persons with chronic illness and their families evolving
through the stages of "naive trust" (ie. believing that professionals will solve health care
problems) and "disenchantment" (ie. becoming "disillusioned" about having placed trust in
the system to do so) when working with the health care system (p. 90). The participants in
this study eventually evolved to the "consumerism" stage identified by Thorne (p. 98).
Consumerism is the act of recognizing that an active role has to be taken in finding services
and sometimes having to use manipulative and defensive strategies to get the care required.

**Availability of Services**

In addition to the lack of services for their children, the mothers in this study also
reported that they needed services for themselves and they found those services lacking and
this finding corresponds with the TBI literature. The importance of emotional and social
support for caregivers of persons with TBI is identified (Acorn, 1993; Brown & McCormick,
1988). Moreover, families' needs for professional help to support, to encourage and to
validate feelings during the early caregiving phases is also reported (Kasowski, 1994). As
well, it is recognized in the literature that respite care for families of longterm TBI "patients"
is essential in order to alleviate social isolation (Testani-Dufour, Chappel-Aiken & Gueldner,
1992). However, Grant and Bean (1992), in their TBI informal caregivers' needs study,
noted that caregivers of "head-injured" adults in the home setting had several unmet needs
that included emotional support, community resources and support groups. The finding of
this present study that there is a lack of several needed services for caregivers of adult children with TBI compares with Grant and Bean's findings.

**Economic Influences**

In this study, the mothers' concerns for having to be financially responsible for their children influenced their Experience of Enduring. Although the TBI literature does not address this specific concern of mothers, the financial burden that TBI imposes on families is well recognized (Carson, 1993; Kozloff, 1987; Lezak, 1988; Mauss-Clum & Ryan, 1981; Willer, Allen et al., 1990). Furthermore, most of the mothers in this study were dependent on litigation outcomes as their only financial resource, thus, those outcomes had far reaching consequences. Similarly, DeJong at al. (1990) reported that monetary settlements or judgements often make the difference between a family's "capacity or incapacity" to meet economic responsibilities (p. 13). As well, they noted that the costs of services for the person with TBI required extensive financial resources and that adequate litigation outcomes would be necessary. The findings of this current study that the litigations outcomes determined the mothers' ability to purchase needed services that would ease the caregiving situation is reflected in De Jong at al.'s findings.

**Consequences**

The mothers in this present study experienced both Gains and Losses as consequences of Enduring the Experience.

**Gains**

The findings of this study indicated that personal growth was a major gain experienced by the mothers. The mothers realized that as they endured the caregiving responsibilities and grasped the reality of the impact of TBI, that they had experienced growth through the adversity. In the literature, growing through adversity fits with the description of the concept
Resilience (Kadner, 1989; Polk, 1997; Rutter, 1981; Wagnild & Young, 1990). Resilience is defined as "the ability to transform a disaster into a growth experience and move forward" (Polk, p. 1). However, in this present study, the findings indicated that the mothers did not view the experience as an opportunity for growth, instead, growth just happened and differs from Polk's definition. Nonetheless, Wagnild and Young found in their research on how resilient older women integrated a major loss into their lives, that over time, as the women continued on to have a purpose in life and had adjusted to the loss, they recognized that they had undergone personal growth and development and had a new dimension. The findings of this present study that the women had not considered the loss to be an opportunity for growth, but growth had occurred parallels Wagnold and Young's findings.

Another way of viewing personal growth is identified in Morse and Carter's (1995, 1996) study of the "patient" or individual experiencing illness or injury. Although they address persons undergoing suffering instead of undergoing adversity, the finding of this current study parallel their description of the "reformulation of self" (1995, p. 45). Reformulation of self occurs when persons undergoing suffering move towards "acceptance of the changed reality", and in doing so they gain new insights and appreciation of life (1995, p. 45). When undergoing a reformulation of self, individuals recognize that because they have endured and suffered that they are "different persons" and that they have a "special strength" (1995, p. 49). Also, they develop a special empathy that can be used to help others who are undergoing enduring and suffering, thus, they will often work towards serving others and advocating for those who are undergoing enduring and suffering. In addition, they revalue life, find purpose in their existence and believe that they have become better persons. The finding of this present study that the mothers' gains included: an increased awareness, compassion, understanding and sensitivity towards others; wanting to advocate for others in
similar situations; undergoing value restructuring; having a changed outlook on life; and valuing the preciousness of life parallels Morse and Carter's reformulation of self. Although, that the women in this present study were caregivers and not "patients" and were still enduring the caregiving experience differs from Morse and Carter.

**Losses**

Several Losses were experienced by the mothers in this study that affected their Experience of Enduring. But, the salient loss for the women was how their children's TBI had shattered their lifespan expectations and had broken their dreams. The TBI literature recounts that parents of adult children who have sustained TBI report that they had expected that at this stage of their lives they would be free from child caring responsibilities and would have had the freedom to do things and make future plans (Brown & McCormick, 1988; Leaf, 1993; Lezak, 1988; Miller, 1991). The mothers in this study indicated that they too had expected to have freedom at this stage of life. Furthermore, another loss of lifespan expectation suggested in this study is that their children would have provided caregiving to the mothers in their old age. Although nothing was found in the literature that addressed that particular issue, the participants' recognition of this future loss corresponds to Rolland's (1994) description of anticipatory loss. Anticipatory loss is delineated by the anticipation of loss over the course of the disability.

The basis for the mothers in this study shattered lifespan expectations was the loss of their former children. The loss for the mothers was intertwined with watching their children experience their loss of their future hopes and expectations. They described that loss as overwhelming and the ensuing feelings of grief as intense. The significance of the loss of their former children compares with the findings of Brown and McCormick (1988) and Martin (1994). They found that families of head injured persons experienced a "loss without
death" (Martin, p. 134), and that the loss was complicated by the person being present in body but forever changed in mind. As well, Martin noted that the grieving process associated with the loss of the former person was extended indefinitely because their presence served to remind families of their losses. Although she did not report on what it is like for families to watch their member struggle with their losses, she did find that families experienced a renewed sense of loss and grief when the head injured member's friends achieved life's milestones such as graduation and marriage. The finding in this current study that mothers experienced a loss of future hopes and expectations compares with Martin's finding. Furthermore, Martin noted that the grieving process of TBI could not be compared with the grieving process of death because in death, the grieved individual is gone and "with time the memories fade in acuity and pain" (p. 136).

In addition, the loss and grief experienced by the women in this study corresponds with the concept chronic sorrow. That is, in Teel's (1991) analysis, chronic sorrow is reported as a recurrent and permanent sadness frequently occurring when a "relationship of attachment is disrupted following an event that renders a loved one forever changed from the hoped-for child or from the known person" (p. 1311). It is caused by the recognition of the "negative disparity" between the person who was known before the "onset of disability...and the now disabled person" (p. 1311). The episodes of sadness do resolve somewhat over time but are precipitated again when recognition of the negative disparity is renewed. Chronic sorrow has been identified as being experienced by parents of children with mental retardation (Olshansky, 1962) and Down's Syndrome (Damrosh & Perry, 1989), and mothers of children with mental illness (Howard, 1994) and chronic illness (Phillips, 1991). The findings of this study that the mothers found their feelings of grief remained corresponds with Teel's chronic sorrow.
Summary

In this chapter, pertinent findings of this study are compared with the available literature. For the most part, little research has been conducted on the Enduring Experience of mothers caregiving their adult children who sustain TBI. Consequently, the discussion examined related literature. Certain components of the study's conceptualization were similar to and supported by those found in the literature. The attributes of enduring described in nursing research are comparable to how it is used in this study. TBI caregiving is found to be an ongoing, onerous experience that requires mothers to develop and implement caregiving strategies to meet the needs of their children. TBI caregiving mothers are shown to demonstrate their capabilities to develop and to use those caregiving strategies. Caregiving tasks other than providing physical care are found to be difficult and overwhelming. Coming to terms with the reality of the TBI is described as a gradual process that requires mothers to recognize and accept the permanent, dramatic changes in their children. TBI caregiving mothers becoming caregivers and feeling responsible for the welfare of their children are enacting basic mothering instincts theorized in the literature. Feeling responsible is found to mitigate caregiver burden as was revealed in this study. Affectionate past relationships are shown to ease the caregiving experience such as TBI caregiving. Taking care of oneself, found to be an essential activity that helped the TBI caregiving mothers maintain their ability to care, has been identified in other primary caregiving studies. "Guarded alliance", required by TBI caregiving mothers when interacting with the health care system, is described as a method used by caregivers of persons with chronic illnesses. Several reports emphasize that TBI caregiving mothers need support, and a needs assessment found several support services lacking for TBI caregivers. The financial impact of the TBI caregiving experience is heavily described and is also seen to be tied in with litigation outcomes. Personal growth through
experiencing adversity, as was realized by TBI caregiving mothers, is presented. Many articles underscore that TBI shatters the lifespan expectations of TBI caregiving mothers. Lastly, TBI caregiving mothers experiencing the loss of the former child as a death and grieving that loss is related to loss of future hopes and expectations.

In addition, several unique insights were identified that include: enduring can be an ongoing caregiver state; accepting the new child results in TBI caregiving mothers having to come to terms with the reality of the onerous responsibility and the impact that responsibility will have on their lives; TBI caregiving mothers are at risk for post traumatic stress disorders; TBI caregiving mothers have a goal to protect the rest of the family from the ramifications of the TBI; mothers define their TBI caregiving situations by using social comparisons; litigation has a direct impact on TBI caregiving mothers; stigma is associated with TBI and is not recognized; personal growth can occur while enduring the experience; mothers recognize that the loss of the former child will impact on their caregiving resources when they are elderly; and chronic sorrow is an ongoing reality for TBI caregiving mothers.

**Limitations**

The results of this study contribute knowledge about the experiences of mothers who are caregivers to their adult children with TBI. Nevertheless, there are some limitations that must be acknowledged. The researchers' novice experience with the research process, specifically the data collection and analysis, may have limited the quality and depth of the findings. However, the analysis was validated with five participants and with three TBI caregiving mothers who were not part of the study. In addition, the analysis fit with the perceptions of professionals working with the TBI population and their families as well as survivors of TBI when presented to them at an international brain injury conference.
Nonetheless, mothers who agreed to participate in this study may represent a select group of mothers caregiving their adult child who sustained TBI, given their ability and willingness to communicate. Therefore, the findings of this study are limited to describing these participants' viewpoints. It would be unsuitable to attempt to generalize the findings of this study to all mothers who are caregiving their adult children who have sustained TBI, and to do so is not the intent of the researcher.

The limitations that have been identified must be taken into consideration when evaluating the results of this study. However, the findings and conclusions derived from this study provides nurses with knowledge that can be considered when they are providing care and support to mothers who are caregiving their adult children with TBI.
CHAPTER 6
Summary, Conclusions, Nursing Implications

Summary

Recent technological advances in emergency medicine, and use of helmets and seat belts have resulted in an increased survival rate of persons sustaining traumatic brain injury (TBI). Thus, TBI is a recent phenomenon. Although it is widely acknowledged that TBI impacts on families and particularly mothers who play a crucial role in the rehabilitation process, little is known about the changes that occur in mothers' lives. This study was undertaken to further understand the experiences of mothers whose lifespan expectations are altered when they become primary caregivers to their previously independent adult children. Using the ethnography method and drawing from Ryan's (1993) a "Lifetime of Mothering" conceptual framework as a basis to collect the data, constant comparative analysis was used. This approach resulted in a descriptive analysis that conveyed a common conceptualization of the experience.

Participants were obtained through the BC Brain Injury Society, Greater Victoria Hospital Society (now known as the Capital Health Region) and the "snowball" technique. Of nine mothers who signed the consent, eight mothers were interviewed with six of those eight fitting the criteria of the study. Interviews were one to two hours in length. Of the six mothers, the length of time post-injury ranged from 3 years nine months to 11 years, the average length of time was 7 years 6 months. Four of the six adult children with TBI were female and two were male. At the time of the interviews, three adult children with TBI lived in their mothers' homes, two had just started to live independently, and one lived in close proximity.
Interviews were transcribed and the transcripts were analyzed using the coding procedure outlined in Strauss and Corbin (1990). The outcomes of the analysis yielded the core category "The Experience of Enduring". The central component of the mothers' descriptions were the processes Becoming a Caregiver, Grasping Reality and Carrying Responsibility.

Although each mother's situation was found to be unique, three major tactics were used by all when Enduring The Experience. These tactics included: Pulling from Within; Comparing in Order to Put a Face On It; and Dealing With It. Dealing With It involved Inside Work and Outside Work. Inside Work encompassed activities directed at holding the mothers and their families together. Outside Work entailed activities dealt with outside the home that were directly related to the caregiving experience.

The uniqueness of each mother's situation was influenced by three Intervening Conditions: Mothers' individual Ways; Availability of Services; and Economic Influences.

As a consequence of Enduring The Experience, all of the women experienced both Gains and Losses. These outcomes had a direct bearing on their Experience of Enduring.

The caregiving experiences of mothers of adult children with schizophrenia in Ryan's (1993) study and mothers of adult children with TBI in this study have both similarities and differences in their experiences. The difference between the chronic illness trajectory of schizophrenia and the permanent disability of TBI affects the experiences.
Conclusions

The findings of this study revealed that, although caregiving throughout the lifespan goes against the expectations of mothers (Greene & Boxer, 1986), mothers with children with TBI endure an ongoing caregiving experience. The experiences were made complicated because TBI is a recent phenomena. The women persisted and persevered in their efforts to become caregivers and to carry the responsibility while all along they sought to comprehend and deal with the realities. Although the structure of each situation was unique, they used similar tactics when they endured the experience. The women experienced Gains and Losses from Enduring The Experience. Conclusions based on this conceptualization include:

1. Mothers' lives are permanently affected by caregiving their children with TBI.
2. Constant caregiving without adequate resources is particularly onerous.
3. Ongoing caregiving of children with TBI has consequences which are both positive and negative.
4. Mothers with TBI caregiving responsibilities over time develop strategies for coping.

Implications for Nursing

There are a number of implications for nursing practice, education and research that would help the mothers to endure the caregiving experience.

Personal Perspectives of Implications

At present, few nurses are involved with helping mothers who provide care to their adult children with TBI in the community. Most professionals and systems involved with these caregiving mothers are focused on the adult child's rehabilitation (ie. occupational therapists, physiotherapists, psychologists, social workers) on the litigation or arbitration process (eg. lawyers and expert witnesses) or on payer aspects (eg. insurance companies or government agencies). This researcher's personal perspective is that there is a generalist role
for nurses in the area of TBI caregiving in the community. That is, because nurses have first hand knowledge of caregiving, they are the most likely candidates to understand the ramifications of TBI caregiving. Additionally, the recent influx of studies addressing the issues of caregivers of the elderly provides evidence of the important role nurses can play in the world of informal caregiving. As well, the findings of this study indicated that there are implications for nursing practice. Therefore, it is reasonable to endorse the perspective that there is a role for nurses on the multidisciplinary team.

**Nursing Practice**

Several implications for nursing practice emerged from the findings of this study. However, before nurses ever become involved on this area, nurses must recognize the uniqueness of TBI caregiving. That is, the findings indicated that many variables exist in each caregiving situation. The distinctive ramifications of each TBI, the level of processes that caregiving mothers are experiencing, the unique attributes of the caregivers and their caregiving situations makes it necessary for nurses to view every situation anew.

The findings indicated that several supportive measures could be provided by nurses that would be helpful to these TBI caregiving mothers. However, when providing support, a salient factor suggested in the findings is that nurses must demonstrate an expert level of knowledge and understanding of the ramifications of TBI. Moreover, providing support to TBI caregivers would require nurses to develop helping, trusting and supportive relationships with them.

The study results indicated a number of direct supportive measures that nurses could provide and that would be helpful to these caregiving mothers. These supportive measures include:
1) **Debriefing and emotional support post accident.** Debriefing is best provided immediately after the traumatic experience. However, opening up the discussion about the traumatic event might seem superfluous to intensive care nurses because of the overwhelming physical needs of the injured children. Therefore, it is incumbent upon community nurses to address this issue and provide mothers with the opportunity to talk about their feelings about the traumatic event. Practitioners can also assess whether the mothers will need any further intensive support.

2) **Loss and grief counselling.** By using open ended questions while providing emotional support, nurses can establish the mothers' level of processing the loss of the former child. When mothers are grieving, nurses can facilitate the process by: providing an environment for the processing of deep feelings around the event; giving mothers the opportunity to grieve openly by using such means as photographs; and encouraging those who are reluctant to openly express grief to keep journals about their feelings. Nurses can address grief responses by: providing appropriate loss and grief literature; discussing grief responses (eg. crying; shock; denial; anger; lack of emotion; apathy); reassuring mothers that grief responses, including chronic sorrow, are natural reactions to the loss; and informing mothers that everyone grieves differently.

3) **Validation.** Nurses can validate: the degree of difficulty inherent in the TBI caregiving situation; the importance that the caregiving has for their children; and the mothers' know-how in meeting the needs of their children.

4) **Encouragement.** Nurses can recognize and acknowledge the mother's resourcefulness in devising, implementing, and evaluating caregiving strategies and in using tactics to hold themselves and their families together. Individual strengths can be mirrored; positive feelings derived from caregiving can be highlighted; descriptions of gains can be
respectfully recognized and acknowledged; and the meaning that those gains have for the mothers can be emphasized.

5) **Education about TBI and caregiving.** Nurses can provide TBI education, but first must carefully assess the educational needs of each mother and must let the mothers' personal experience serve as a basis. The findings indicated that it took awhile before mothers understood the full ramifications of the TBI and before they could grasp the reality of their situations. Therefore, knowing when to provide specific TBI information is paramount, and is best handled by the distribution of general written information that can be used as a resource when mothers are ready. Nurses can provide caregiving education such as: being assertive when working with health care teams; preparing mothers for reactions from health care team members when an assertive approach is used; and problem solving skills that can be used for such areas as how to bridge with a society that lacks knowledge about TBI (eg. help to identify what can be controlled and working on ways to control it).

6) **Handling unexpected social situations (stigma management).** Nurses can confront stigma issues by: working with mothers on how to handle anticipated difficult social situations; providing information on stigma management; and by reassuring mothers that protecting their children from society's stigma is a natural mothering response. In dealing with stigma, the findings of this study suggested that most mothers had restructured their own values about persons with obvious disabilities. When mothers are undergoing value restructuring, nurses can provide emotional support.

7) **Support groups.** Nurses can provide support groups to: give mothers a place to have understanding interactions with members who would have had similar experiences; alleviate social isolation; offer participants a place to develop supportive social networks; provide the milieu for sharing (eg. feelings, events, experiences, practical information about what is
available, and the quality of professional resources; and educational programs (e.g. how to lobby for change in government policies). Nurses must have an evaluation system built in to the support groups, and when providing educational programs they must use adult learning theory (Knowles, 1988). However, nurses must always be cognizant that support groups are not for everyone.

9) Advocacy. The lack of care delivery systems has a salient influence on mothers' caregiving experiences. Because these caregivers lack the stamina and/or are not free to advocate for needed changes to governmental policies regarding care delivery systems for populations with TBI, it is critical that nurses become proactive. Nurses could advocate for: (a) respite services; (b) quality longterm care facilities; and (c) support services for caregiving mothers. Although the findings indicated that some of these services were available, mothers often found they did not measure up to an acceptable standard. Consequently, nurses could be involved in: developing quality assurance guidelines; evaluating programs; and providing TBI educational programs to community support workers and auxiliary service providers.

10) Case management. Community focused case managers could provide a liaison from acute care settings or rehabilitation centres and would alleviate the abandonment experienced by TBI caregiving mothers. Nurses as case managers could: provide initial support; assess caregiving situations and liaise and collaborate with multidisciplinary teams in the preparation for caregiving in the home; and be in a position to develop trusting supportive relationships. On a follow-up basis nurses as case managers could: (a) help with problem solving by giving different ideas; (b) provide crisis intervention; (c) continue linking and collaborating with multidisciplinary teams; (d) provide TBI education as needed; (e) give emotional support to mothers (e.g. grief and loss, PTSD and post litigation counselling); (f) advocate for services;
(e) help with placements; (f) provide medication information when applicable, and monitor the provision of medications; and (g) validate the caregiving situation on an ongoing basis. Case managers would help ease these mothers' overwhelming TBI caregiving experience that puts them at risk for health problems of their own. In doing so, nurses would be contributing to the promotion of caregiver health.

**Nursing Education**

If nurses are to become more involved in helping mothers who are caregiving their adult children who have sustained TBI, then nursing education will have to reflect that commitment. The results of this study revealed that many professionals and service providers lacked sufficient knowledge about TBI and the communication skills to work collaboratively with the mothers. In this regard, implications for nursing education includes knowledge of TBI and its' ramifications and the interpersonal skills needed in order to be supportive.

What was particularly evident from this study was that nurses need knowledge of the unique feature of an ongoing caregiving experience. To this end, the existing knowledge of informal caregiving including caregiver burden and management has to be provided. In doing so, it is important to emphasize that delineating caregiving activities of mothers of children with TBI is still in its infancy. However, the education about the common knowledge of caregiving will prepare nurses to delineate the unique parts of the caregiving experience for mothers of individuals with TBI.

Another implication would be education about the concepts loss and grief, grief responses, chronic sorrow and the potential for post-traumatic stress syndrome. A practical component should be included that would allow students to observe how experienced nurses provide support to mothers when grieving the loss of their former child and when debriefing the trauma scenario.
The study question: "What are the experiences of mothers whose lifespan expectations are altered when they are required to become primary caregivers to previously independent adult children who re-enter their lives as dependent adult child as a result of traumatic brain injury?" was approached using the ethnography method for data collection and the constant comparative analysis method for data analysis. The resulting conceptual framework provided a basis for further research. The areas of investigation arising from this study that are worthy of examining include:

1. To address the limitations of this study further qualitative studies of caregiving are required using a larger sample of caregiving mothers of adult children with TBI. The sample should include a more heterogenous group of mothers from various backgrounds.

2. In this study, the majority of adult children were female although the majority of TBI's occur in males. Thus, further research is needed to explore the relationship between the gender of the child with the TBI and the mothers' feelings of responsibility for the child.

3. Further research is needed to determine what sets mothers with children with TBI who caregiver apart from mothers with children with TBI who choose not to take on the primary caregiving role.

4. There is a need to explore how the dynamics of mothers' previous relationships with their children, that is, prior to their children's TBI, impacts on their TBI caregiving experience.

5. Research is needed to explore the experiences of mothers when they place their children into acceptable placements.

6. Research is needed to identify the impact that the TBI has on the lives of the other siblings and the other parent.
7. Research is needed to explore post traumatic stress in TBI caregiving mothers. Research is needed to identify how nurses can help mothers work through post traumatic stress.

8. Research is needed to explore the litigation experience of TBI caregiving mothers.

9. Research is needed to further explore the experience of loss and grief in TBI caregiving mothers.

10. Research is needed to explore the impact of the stigma of TBI on TBI caregiving mothers.

This chapter has provided the summary, conclusions and nursing implications arising from the findings of this study.
References


Grad, J., & Sainsbury, P. (1968). The effects that patients have on their families in a community care and a control psychiatric service - A two year follow up. British Journal of Psychiatry, 114, 265-268.


Appendices
Appendix B

Introductory Letter to Participants

My name is Barbara Tabata. I am a Registered Nurse presently enrolled in the Master of Science in Nursing program at the University of British Columbia. My professional and personal experiences, has lead to my interest in what mothers go through when their independent adult children sustain traumatic brain injury. For my thesis, I am conducting a study to learn more about the experiences of these mothers who are living with these children. I am interested in describing this experience from the perspective of the mothers themselves.

If you are a mother who is presently living with your child, who as an independent adult sustained a traumatic brain injury at least one year previously, I would like to invite you to participate in this study by sharing your experiences in a confidential, unstructured interview. As a participant, you will be asked about your experience of having your child sustain a traumatic brain injury. In an interview, I will ask you about the changes that have taken place in your life as a result of the traumatic brain injury in your child.

Participation in this study will involve one to two personal interviews by me, that will last approximately one hour. The interviews will be conducted at a time and a place that is suitable for you and that ensures a private, uninterrupted atmosphere. The interviews will be tape-recorded and those tapes will be transcribed to help me remember the information that has been shared. The tapes will be stored in a locked cupboard and only my thesis committee and myself will have access to them. Once the study is finished they will be erased.

If you do participate, your identity will be kept confidential. Your name will not be used during the interview and if inadvertently it is, then that portion of the tape will be erased. Your name will not appear in any transcribed material, written reports or future publications. Your tapes will be assigned a code known only to me and kept in a locked cupboard. Although passages from the interviews might be used in the report of the study, these may be recognized by you, but not to others.

Your participation in this study will be voluntary. You will be free to withdraw at any time and to decline to answer any questions. Your decision to participate or not will not effect any health services.
I have read the above information and I have had the opportunity to discuss the study with the Co-Investigator and ask questions to help me understand what my participation would involve. I have had my questions answered to my satisfaction. I freely consent to participate in the study and acknowledge receipt of a copy of the consent form.

______________________________ Date
Signature of Participant

______________________________ Date
Signature of Witness
Appendix D

Ethnodemographic Data Collection Sheet

Code Number: _________________________

1. Age of Child: _________________________

2. Gender of Child: M: F: _________________________

3. Date of Child's Injury: _________________________

4. Child was living with mother when injured: Yes: No: _________________________

5. Length of time child has been living with mother since the injury: _________________________

6. Employment status of mother prior to child's injury:
   Unemployed _________________________
   Unemployed and seeking employment _________________________
   Unemployed and receiving assistance _________________________
   Employed full time _________________________
   Employed part time _________________________
   Retired _________________________

7. Employment status of mother after child's injury:
   Unemployed _________________________
   Unemployed and seeking employment _________________________
   Unemployed and receiving assistance _________________________
   Employed full time _________________________
   Employed part time _________________________
   Retired _________________________

8. Mother belongs to British Columbia Head Injury Society: Yes: No: _________________________
Appendix E

Sample Interview Questions

1. **Grand Tour Question** (Spradley, 1979)

   What has it been like for you since your child sustained the traumatic brain injury?

2. **Descriptive Question** (Spradley)

   Could you tell me about your experience of having your adult child live with you since the injury?

3. **Structural Question** (Spradley)

   What changes have taken place in your life since your adult child with TBI began living with you?

4. **Contrast Question** (Spradley)

   What is the difference between your life before your child sustained the brain injury and now?


   How has your child's TBI affected your relationship with your child?

   What have you done to manage any changes in your child's behavior?

   What would you say is the extent of your involvement with your child since the TBI?
   - How have you managed to cope with this involvement?

   What is the extent of your involvement in any services that your child might require because of the TBI?
   - How have you managed to cope with this involvement?

   How has any changes in your child affected you personally?
   - How have you managed to cope with this impact?