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ABSTRACT

Many families have experienced the pain of living with a family member who has a neurological illness. This experience has far reaching implications for all members of the family. For some people, this experience makes them feel closer to their families, for others it is too painful and causes detachment.

Informed by ecological systems theory, structural family theory and theories on loss and grief, a qualitative study based on semi-structured personal interviews was conducted. The sample consisted of four women and one man who had experienced neurological illness in their families. These interviews were recorded, transcribed and analyzed for emergent themes. The analysis of the data gives voice to five courageous family stories.

The first emergent theme explores some of the challenges faced by participants at the onset and during progression of their family member’s illness. Theme two focuses on the divisive reactions of family members and tensions in family relationships. Connective reactions and supportive relationships encompass the third theme of discussion. The fourth cites adaptive strategies used by participants in coping with their experiences. The fifth theme of growth and meaning reports on participants’ enhanced philosophical views on life. Finally, a therapeutic model towards healing demonstrates the themes and data presented.

The findings of this study support the integration of patient-centred care in the acute hospital setting and raise questions about the roles of the hospital and the community in discharge planning. The implications for social work practice include the importance of a healing component in any family therapy
model, recognition of the power of relationships in healing and the ability to acknowledge and stay with clients’ pain. It is recommended that future research be conducted in this field with specific reference to varied cultural perspectives on illness and loss, multigenerational studies of families dealing with illness and loss and peoples’ coping abilities in the face of adversity.
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INTRODUCTION

BACKGROUND TO THE PROBLEM

I have acquired a special interest in working with patients with neurological illness and their families. Having practiced social work solely in the health care field for over eight years, I have been privileged to be part of patients' and their families' extreme happiness and joy as well as their raw pain and grief. Families' abilities to deal with traumatic experiences have always impressed me. Each family has a unique way of dealing with change and expressing its grief.

Many families are confronted by traumatic experiences in their lives that may be so intense and shocking that they shatter the security of daily existence. Neurological illness can be considered such an experience. This has far-reaching consequences for all members of the family. Events such as a neurological illness vary according to predictability, suddenness, duration of impact, controllability and the extent of damage (Figley, 1995). McCann and Pearlman (1990) conceptualize an illness experience as traumatic if it is "sudden, unexpected or non-normative, exceeds the individual's perceived ability to meet its demands, and disrupts the individual's frame of reference." (p.10).

There is much literature written about families coping with serious illness and loss (Shapiro, 1994 and Ell & Northen, 1990). There are also unique problems faced by individuals and families living with neurological
illness. Bernstein (1990) shows that the needs of families living with neurological illness include a need for communication, a need for honesty and a need for reassurance. Elliot and Smith (1985) suggest that when there is neurological illness it is important to recognize each family's individual needs in order to enhance the potential for long-term recovery. A common theme of these accounts was the fact that the family living with illness also lives with a lot of pain and grief. This study will focus on exploring the ways in which individuals are able to cope with serious illness and loss within their family systems. This study will give voice to the profound personal experiences of five individuals whose families had experienced varying neurological illness.

**STATEMENT OF THE PROBLEM**

Being part of a family in which one member has a neurological illness can be a painful experience. Individual family members have different ways of dealing with traumatic experiences such as illness, and of coping with their grief. For some people, this type of experience could make them feel closer to their family, for others it may be too anxiety provoking and could cause separation or detachment. This study will explore the changes individuals in the family may have to make in this process. It will document the ability of individuals to heal their pain and their courage to move forward in the face of adversity.
The purpose of this study is to gain more insight into individual family members’ experiences of coping with illness in the family. This study will explore families’ unique ways of adapting to illness, loss and grief.

**OVERVIEW OF THEORETICAL FRAMEWORK**

The following is an overview of the theoretical framework which will be presented in greater depth in Chapter One.

Ecological systems theory will be the integrated macro perspective used in this study. This theory situates the family within its own ecological system, e.g., religious affiliation, neighbourhood, culture etc., and is useful to gain an understanding of how the family and important environmental systems interact and influence one another. When studying the family coping with illness and grief, it is essential to explore the transactions between the family and other important systems such as the hospital, social support and religious institutions. The environment consists of an interwoven process of relationships between individuals, the family system and the environment.

The nature of exchanges (energy flow) within the family and how they influence each other is of particular relevance to this study and structural family theory is chosen as an appropriate micro theory. This theory attends to specific role structures by which particular family members strive to maintain homeostasis within the family.

Grief and loss theories are appropriate as micro theories for this study and assist in exploring the impact of illness on individuals in the family. Loss
and grief theories emphasize the interpersonal and interactional nature of grief in the family and are therefore an important focus of this study.

**IMPORTANCE OF THE ENQUIRY**

This study will focus on the impact of illness and loss on the family system, as experienced by individual family members. It will give voice to the lived experiences of five individuals coping with neurological illness in their families.

I hope that this study will elicit the interest of other health care professionals and assist them in their work with families, especially those families having to deal with serious illness. I also hope that this study will stimulate further research in the fields of family therapy and health care.

**ORGANIZATION OF THESIS CONTENT**

The thesis is comprised of four chapters. In Chapter One, a review of the literature is presented in two major sections. The first section focuses specifically on the theoretical framework and explores systemic theories of the family and looks at theories of grief and loss. The second section focuses on research literature linking illness and perception of personal growth. Chapter Two describes the research methods and procedures that were used.
In Chapter three, a description of the study participants and a discussion of the research findings are presented. Finally, the summary, conclusion, implications for social work practice and recommendations for further research are developed in Chapter Four.
CHAPTER ONE: REVIEW OF THEORETICAL AND RESEARCH LITERATURE

INTRODUCTION

In this chapter, a review of the literature is presented in two major sections. The first section focuses specifically on theoretical frameworks related to the family coping with illness and loss, with reference to systemic theories and the constructs of loss and grief. In section two, I review concepts of personal growth and benefit through illness and trauma.

THEORETICAL FRAMEWORK

The theoretical framework of this study incorporates ecological systems theory as the integrated macro perspective. Structural family theory and theories of grief and loss are chosen as appropriate micro theories for this study.

Ecological Systems Theory

Systems theory proposes that all organisms are systems made up of subsystems and part of suprasystems. This theory offers useful understanding of the individual’s (microsystem) interactions with his/her wider social context. The individual’s external world consists of a mesosystem (neighbourhood, family, etc.), an exosystem (policies, laws, etc.) and a macrosystem (culture, economy, etc.). Systems theory can be well applied to the family as a social
system. Siporin (1980) believes that systems theory refers to a cognitive construction of reality necessary for the understanding of and operation within the intervention situation. The family is an open system which has boundaries where energy is exchanged both within the system and with other external systems. This perspective provides ways of understanding how family members interact and influence other systems. This is significant for this study, as it looks at how the family perceives the environment when illness occurs. Systems are defined by certain characteristics. These include equilibrium or homeostasis, which is the ability of the system to maintain itself even though outside influences may impinge on the system (Payne, 1997). The family and its individual members often have a need to maintain themselves when crisis and ongoing stress prevail. Reciprocity refers to the theoretical proposition that change in one part of the system causes change in all other parts. This is particularly evident in the family living with neurological illness, as all members are affected, although in different ways (Bernstein, 1990).

Living systems such as the family must try to maintain a good fit with their environment. Transactions are ongoing and generally neutral; however, the nature of transactions between systems can disrupt equilibrium. When transactions upset this fit, stress is produced and problems between the system and the environment result. In a family coping with illness, anxiety levels are increased and there is often evidence of stressful transactions between the family and its environment.
Allen-Meares and Lane (1987) suggest that "the ecological systems (ecosystems) theory is emerging as a macro-level theory that offers promise as a unifying paradigm for social work knowledge and practice." (p. 515). Pincus and Minahan (1973) apply systems ideas to social work practice. The principle of their approach focuses on the premise that people depend upon and interact with systems in their immediate environment and social work should focus on these interactions. When a family is dealing with illness there may be daily interactions with societal systems such as the hospital, as well as more informal systems such as extended family and friends.

The environment consists of an interwoven process of relationships between family, environment and behaviour. Ecological systems theory helps us to look at their mutual interdependence and mediated transaction. These can be either positive or negative and will effect family functioning and homeostasis. Some family systems are able to reconfigure and adapt to disequilibrium, even though there is constant stress in the environment and the family is having to cope with daily transitions. On the other hand, life events such as illness can upset adaptive balances and the family may experience a sense of loss of control. This promotes increased stress and crisis within the family unit. In these situations families' adaptive capacities and ability to maintain homeostasis is also dependent on their perceptions of the life event and each family's personal and environmental circumstances. Some families have a network of support and feel that the world is responsive to their needs. Other families may feel isolated and perceive the interface between themselves and the physical environment as stressful and maladaptive (Pincus
& Minahan, 1973). It is important to further explore how individuals in the family cope with these types of experiences and structural family theory focuses on specific role structures within a family system.

**Structural Family Theory**

Structural family theory looks at interactions between individuals within the family and forms the basis for understanding family organization. As a micro theory, it provides understanding of family functioning in order to explore how families cope with traumatic illness. Structural family theory proposes that the family is a purposeful, self-regulating system which is geared towards adaptation and structure maintenance. One of the assumptions of this study (see page 23) is that changes in family structure contribute to changes in the behaviour and inner psychic processes of family members. Individuals respond to stress within the family system and also contribute to stress within the family. The family as a unit strives to meet the requirements of external systems in the environment as well as the internal needs and demands of its members. This supports the argument that when a family is forced to cope with illness the family structure undergoes changes and individual members respond to this differently. Hill (1971) reinforces this by stating that “New behaviour patterns accordingly develop in all of the family positions as a result of the changed activities of one person.” (p. 306).

Jones (1980) outlines four important concepts in structural family theory. These include: systems, subsystems, family structure and transactional patterns. Individuals in the family establish patterns of
interactions that become rules which govern and determine family behaviour. Concepts of structure such as position, roles and norms tell us about reciprocal features present in family structure. This theory also attends predominantly to boundaries, coalitions and power structures. Clarity of boundaries is often a good measurement tool for assessing healthy family functioning. Subsystems within the family consist of two (dyads) or more individuals. Each system has its own boundaries, rules and expectations.

Structurally, rules are sets of behaviours that are attached to expectations and become patterned over time. It is through subsystems that family members differentiate and carry out tasks and functions. In a family where one member has a serious health problem, individuals in the family may be forced to form new alliances and subsystem formations may change. The family strives to assist its members in performing tasks and functions. In the event of a crisis or sudden change, this often leads to breakdown in family structure or inability to perform basic tasks and be responsive to the changing environment.

It is essential in this discussion of family structure to introduce the notion of roles. The assignment of roles depends upon how the family organizes itself into various subsystems. The types of roles that may occur are either ascribed or acquired ones. Following serious illness, family members may be assigned new roles or role blurring may occur. Role assignments may be dependent on which family member is ill. If a parent has a neurological illness, role changes may be marked as siblings may be forced to take on parental roles either temporarily or on a more permanent basis. This is likely to have some negative effect on the family system and the system may cease to
function. Evidence of breakdown can include lack of role complementarity and loss of effective boundary maintenance between subsystems. Minuchin (1974) believes that "when the structure of a family group is transformed, the positions of the members in that group are altered accordingly. As a result, each individual experiences change." (p.2). This is exactly what happens in most families living with illness and grief.

Participation in a system induces members to interact in a complementary way to produce a form of shared value. Families promote member-to-member interaction in order to ensure that their two important functions of survival and emotional development are attained (Roberts, 1990). Individuals are part of different subsystems in which they experience different levels of power and differentiation skills. Interdependence and interconnectedness of family members lead to a network of interactional patterns which link family members in different positions together. These patterns are based on shared expectations that make a family unique and enable it to perform tasks. When a family deals with illness and grief there is often evidence of subsystem shifts, boundary changes and triangulation. Any system which is not overly rigid can usually assimilate change, recalibrate structural elements to maintain itself, while making modifications (Shapiro, 1994).

The family boundaries are determined by the interaction and degree of interdependence between significant others. Boundaries are rules that define participation between two subsystems. If boundaries are unclear, as may be
apparent in a family living with illness, two extremes may occur. These are either enmeshment or disengagement. Minuchin (1974) defines enmeshment as a tight interlocking, whereas he says disengagement is a disconnectedness. The family is an open system continually facing demands for change. A family can only introduce a few new elements of change at a time to assimilate them easily. If more elements are introduced, the system cannot accommodate this without restructuring itself and making a conscious effort to seek outside assistance. These changes may increase the level of stress and anxiety within the family system and individuals may experience feelings of loss and grief.

The family system can be conceptualized as an emotional unit. Structural family theory assumes that the existence of differentiation, as well as the concept of togetherness, keep members of a family emotionally connected and emotionally reactive to one another. When an illness is introduced into the system there are changes in family structure and organization. Kerr (1988) believes that “As the level of anxiety increases, people experience a greater need for emotional contact and closeness and simultaneously, in reaction to similar pressures from others, a greater need for distance and emotional insulation.” (p. 50).

The literature provides evidence that adjustments of living with a critically ill person have a huge influence on the family (Florian, Katz & Lahav, 1989). As a direct consequence the family often experiences a consistent and sometimes increasing burden over an extended period of time. Often a family’s first priority in managing the crisis of grief is re-establishing the equilibrium
necessary to support ongoing family development. Resources may include individuals within and outside of the family, the family system itself, the community and the socio-cultural environment. The integration of social, cultural and ecological perspectives of human development can further our understanding of family grief from a systemic perspective.

Lezak (1978) did studies on the impact of loss on a family system and reports that families living with illness experienced enforced isolation and loneliness. He describes a reduction of social activities in his study and concludes that families living with a chronically ill family member tend to limit social relationships so as to avoid confrontation between their denial and the community’s frequently negative perceptions of illness.

Neurological illness of a family member creates a structural void within the family that requires homeostatic adjustment. Bowlby-West (1983) states that common homeostatic adjustments in a family include scapegoating, enmeshment, disengagement and role reversals. Bowlby-West believes that these adjustments will be especially needed if family members are unable to talk about their grief emotions or repress them.

Grief and Loss Theories

The need for re-adjustment is also documented by Kubler-Ross (1969). In her theories on grief and loss, she writes about stages of grief which people work through during times of stress. She maintains that family members should be allowed to express themselves openly and talk about their anger,
pain and hope, and be free to go through stages of denial, bargaining and accommodating acceptance. Kubler-Ross believes that these are healthy stages with no time limitation and the more this pain and grief can be expressed, the more bearable it becomes. It can be argued that theories of this type are linear and limited in their scope and applicability (Burnett, 1994). They tend to point towards resolution and may not be able to be applied to different types of families.

More contemporary approaches to loss define phases as heuristic tools which are descriptive, rather than as a set of rules or prescriptions for where an individual ought to be in the "normal" grieving process. (Shuchter & Zisook, 1993). The process of loss is often viewed as being comprised of a number of basic tasks that must be accomplished. These tasks do not follow in a specific order (Kleber & Brom, 1992). The concept of recovery has also been the subject of careful consideration, with Weiss (1988), for example, inquiring whether grieving persons ever "get over it", or whether one should substitute new terms such as "adaptation" or "accommodation". In short, there has been growing recognition concerning the individual and cultural heterogeneity of responses to loss and the multidimensionality of grief reactions. (Stroebe, Van den Bout & Schut, 1994).

The scientific study of loss is a comparatively young discipline and despite its progress in the last couple of decades, it is still lacking in empirical research on many basic phenomena, theoretical formulations and psychometrically sound instruments (Stroebe et al., 1994). Researchers and
writers in the field of grief have described a plethora of symptoms and other phenomena associated with a grief reaction and its resolution. However, little evidence exists as to the frequency of grief reactions across time (Burnett, 1994). Wortman and Silver (1989) propose that this lack of knowledge of grief reactions has led to the adoption of incorrect hypotheses, faulty conclusions being drawn from empirical studies and the perpetuation of myths that have no empirical foundation. One notable area of contention in the bereavement literature is around stage or phase models of bereavement, which propose that individuals will progress through various stages which end with the stage of recovery or resolution. As a result, individual differences in duration, intensity, and nature of grief reactions are neglected (Kleber & Brom, 1992). Moreover, numerous researchers (Burnett, 1994, Cleiren, 1993, Wortman & Silver, 1989 and Lehman, Wortman & Williams, 1987) have questioned the usefulness of such models. Despite criticism, positive learning has emerged from grief and loss theories and this learning has formed the basis for ongoing understanding and research in this field.

**RESEARCH LITERATURE**

**Neurological Illness**

A review of the literature on illness, particularly neurological illness, (Elliot & Smith, 1985) reveals the existence of increased emotional anxiety, high levels of stress and high rates of depression, anger and guilt, as main characteristics of family members coping with this type of illness. When there
is neurological illness in the family, structural changes in the family system are likely to occur. Shapiro (1994) states that these structural changes have two dimensions. One involves impaired function of family roles caused by illness and family members’ incapacitating grief, the other dimension involves the loss of a stabilizing member to maintain family equilibrium. In families dealing with illness, both these dimensions may be present within the family structure.

Reiss (1981) concludes that families living with a member with a serious illness construct shared meanings of understanding the illness. He says these meanings either enhance or impede processes of growth through experience.

Shapiro (1994) explores variations of illness in terms of onset, course, outcome and incapacitation. She states that these psychosocial aspects of illness, and the phase of the process of illness interact with family characteristics to determine family responses and adaptations. Families’ hopes for positive outcomes and their despair at the reality of the prognosis may increase their grief and maladaptive patterns.

Trauma

Many individuals are confronted by traumatic events in their life. Taylor and Armor (1996) conceptualize trauma as a “disruptive negative event that produces life disturbance and at least temporary aberrations in psychological functioning...” (p. 874). Neurological illness can be classified as such an event. It takes considerable time and effort for the individual to once again be able to lead a life without being pre-occupied with the traumatic event (Kleber & Brom, 1992). Traumatic events vary according to predictability, suddenness,
duration of impact, controllability and the extent of damage and destruction (Figley, 1995). McCann and Pearlman (1990) conceptualize an experience as traumatic if it is “sudden, unexpected or non-normative, exceeds the individual’s perceived ability to meet its demands, and disrupts the individual’s frame of reference and other central psychological needs and related schemes.” (p. 10). Each person’s experience of trauma is so different that there is much discussion about what may constitute trauma. Nevertheless there is general consensus that a traumatic event is one in which a person is flooded with intense stimulation that she/he cannot control. Furthermore, powerlessness, acute disruption of one’s existence and extreme discomfort characterize a traumatic experience. It is important to note that many conditions, including physical and psychological development, age, specific circumstances in which the trauma occurred, influence and impact on the individual’s response to a particular traumatic event (Cerney, 1995). Whilst experiencing traumatic events such as the illness of a close family member, feelings of loss and grief are often reported.

**Loss and Grief**

Grief is commonly regarded as the most generally experienced symptom of loss, but it is by no means the only one (Cleiren, 1993). Appetite loss, insomnia, lethargy, withdrawal, loss of interest in life, anxiety attacks, depressed moods, suicidal thoughts, anger, guilt, numbness, hallucinatory experiences, but also relief and hope, may be experienced in rapid succession and alternation (Valeriote & Fine, 1987). Loss can also be detrimental to one’s
mental health and can potentially create or exacerbate emotional problems of clinical magnitude, although most grieving persons adjust to the loss without such extreme consequences (Stroebe et al., 1988).

In the loss and grief literature one encounters terms such as bereavement, mourning and sadness. Raphael (1983) notes that grief is the reaction to the loss of a close relationship and is conceptualized as the emotional response (sadness, anger, despair, helplessness) to the loss.

**Construing Meaning from Adversity**

The literature over the past 25 years reveals ample evidence of the search for meaning from adversity. A review of the literature about the psychological aspects of major medical problems shows that many people cited benefits from their adversity. This is evident from studies of survivors of spinal cord injuries (Bulman & Wortman, 1977) and stroke victims and their caregivers (Thompson, 1991). Frankl (1969) believes that one’s suffering becomes meaningful as one confronts it, displaying an ability for self-transcendence, and an ability to detach oneself from the predicament and to change one’s attitude. In this way one is able to accept fate and add deeper meaning to life. Self-transcendence (the capacity to rise above conditions whether biological, social or psychological) becomes a central metaphor for personal growth resulting from trauma (Frankl, 1969). This, however, can only be achieved through acceptance of the trauma which is particularly difficult, but essential for moving toward resolution (Frankl, 1969).
Before the 1980's little systematic research had addressed the topic of searching for meaning in undesirable life events (Silver, Boon & Stones, 1983). Still, most research focuses exclusively on the negative outcomes of trauma (Park, Cohen & Murch, 1996). There is, however, some research to suggest that individuals are able to find meaning in experiences such as accidents, and serious illness (Baures, 1996). These findings lend support to the view that crisis can stimulate positive shifts in life-perspective and heighten an awareness of the human condition (Kessler, 1987), be an opportunity for spiritual growth (Hall, 1986), produce an improvement in psychological functioning, increase the search for an expanded and more meaningful perspective of existence (Decker, 1993), and improve self-concept, coping skills and social relationships (Park et al., 1996). In fact, Debats (1996) found that there is a substantial and consistent relation between meaning in life and psychological well-being. A sense of meaning in life was found to be a potent predictor of psychological adjustment after traumatic events. Taylor and Armor (1996) believe that when people are faced with stressful events their perception may become marked by positive biases such as self-aggrandizement, unrealistic optimism and an exaggerated sense of control. These researchers postulate that traumatic events such as illness challenge these beliefs and individuals attempt to restore or enhance them. Existential psychotherapist Irwin D. Yalom (1980) proposes that individuals can experience two types of meaning – cosmic and secular. Cosmic meaning refers to an overall life order, pattern or sense of coherence surrounding life's occurrences. This may be formulated by a belief in God or a higher power than
oneself. Secular meaning pertains to meaning experienced as a result of believing life is comprised of purposes to be fulfilled.

Jaffe (1985) considers the process of self-renewal (the creative restructuring of the self) as a possible response to adversity such as illness in the family. Through self-renewal, one's personality may expand to accommodate new experience, and new levels of capacity and awareness may develop. Self-renewal usually begins a long time after the traumatic event: changes only begin to occur as one releases feelings of pain, self-pity, anger or helplessness. People feel qualitatively different without denying or forgetting the difficulties they experienced. In essence, self-renewal encompasses a meaningful, intense, profound and transformational experience.

Thompson and Janigian (1988) propose that individuals have life schemes that provide a sense of order and purpose in one's life. A life scheme is a cognitive representation of one's life, much like a story, which organizes one's perspectives of the world and oneself, goals one wishes to attain, and events that are relevant to those goals. The meaning of an event is derived from the extent to which the event helps one reach important goals. Traumatic events, such as serious illness, have the capacity to challenge parts of the life scheme, disrupting one's sense of order and purpose. Finding meaning, therefore, becomes a process of changing the life scheme so as to accommodate the traumatic experience and its ramifications, or changing one's perception of the event by emphasizing the positive aspects of an essentially negative event. In this way, feelings of order and purpose are restored.
Freeman (1998) believes that pain is a healing emotion and an opportunity for connection and personal growth. Seigel (1990) expands upon this concept of embracing pain and proposes that one could learn to use one’s pain for personal transformation. Freeman (1998) provides evidence that when people are able to acknowledge and embrace their pain and express the depth of their pain, then the healing process truly begins. This is the core of his theory of pain as a sacred emotion, that can bring people together and help them make meaning out of traumatic experiences.

Meaning is often discovered or imposed through the concept of purpose. (Janoff-Bulman, 1992). By choosing to positively construe aspects of an illness, meaning can be found in suffering. Although there may be numerous possibilities for positive interpretations of traumatic events, two types of interpretations are particularly common. The first involves perceiving the victimization in terms of important lessons learned and benefits derived for oneself. These lessons often involve a renewed appreciation of life and oneself, a reconsideration of what is important and precious in life, and a newfound awareness of one’s strengths and possibilities. The second interpretation entails understanding the traumatic experience in terms of benefits for others (Janoff-Bulman, 1992). This involves turning the victimization into a personally altruistic act. Self-help groups such as Compassionate Friends have arisen out of the anguish of bereaved parents and have had positive personal and social impacts. The fact that survivors are able to confront their experience and re-establish some of their prior assumptions in light of the tragic experiences suggests the prodigious capacity of individuals to survive
and cope with extreme adversity. There is a feeling of personal triumph, of
mastery in spite of the extraordinary difficulties and demands of the
experience. There is also a sense of possessing a new, special sort of wisdom,
which derives from the most potent type of education – personal experience.
The trauma survivor emerges somewhat sadder, but considerably wiser (Janoff-
Bulman, 1992). Freeman (1998) perceives that wisdom is something from
within, guided by an inner sense of what is right. A wise act is one that
honours the integrity and specialness of the situation. It is devoid of
judgement and has the potential of bringing out the best in the situation.
Freeman (1998) believes that wisdom includes knowledge but also goes beyond
knowledge. Wisdom is the search for deeper understanding and considers
what is not known or understood; it allows for the using of the spiritual, moral
and emotional aspects of a situation as a guide to understanding and action.

Tedeschi and Calhoun (1995 and 1996) explore benefit-finding in
traumatic experiences and organize growth from traumatic experiences into
three categories, namely; changes in self-perception, changes in inter-personal
relationships and a changed philosophy of life. One class of benefits cited by
individuals who have faced difficult experiences such as serious illness are
changes in the perception of the self. Experiencing trauma provides a
substantial amount of information about self-reliance that is significantly
elevated beyond what it was before encountering the difficult challenge of the
trauma. Surviving trauma may also result in an enhanced appreciation of
one's vulnerability, sensitivity and emotional experience (Tedeschi & Calhoun,
1995 and 1996). The recognition of one's vulnerability can lead to more
emotional expressiveness, willingness to accept help, and therefore, an employment of social supports that had previously been ignored. There may also be increased compassion, greater sensitivity to the needs and feelings of other people, and efforts directed at improving relationships. People who suffer from illness may be more likely to offer support to others in turn (Tedeschi & Calhoun, 1995 and 1996). Survivors of stressful events may gain a new found appreciation for life and an acute recognition that their time and relationships are precious. Grappling with significant life challenges such as serious illness may lead to a strengthening of religious beliefs, spiritual affiliations and questions relating to the purpose of life (Tedeschi & Calhoun, 1995 and 1996).

ASSUMPTIONS

Based on the theoretical framework and review of the literature, the research assumptions about living with illness and loss that guide the focus of this study include:

- When one family member has a serious health problem, this will have repercussions for other family members, and individuals’ roles, boundaries and communication patterns will change to a significant level.

The structural approach to family therapy (Jones, 1980) focuses on interaction between individuals within the family. Structural theory forms the basis for understanding family organization and family functioning. In fact, Minuchin (1974) found that family structures such as boundaries, roles and power relations would change significantly if the family was continually faced
with demands for change. Elliot and Smith (1985) suggest that serious illness places constant demands on individuals in the family.

- *The family as a unit has different ways of coping with loss and expressing grief.*

  Allen-Meares and Lane (1987) believe that anxiety levels are increased in a family coping with serious illness and that there is often evidence of stressful transactions between individuals in the family. These interactions can be either positive or negative and will affect family functioning and homeostasis. Payne (1997) argues that some family systems are able to reconfigure and adapt to disequilibrium, even if there is constant stress and daily transition in their environment. However, for some individuals, life events such as serious illness can upset adaptive balances within the family system and this promotes increased stress and crisis within the family unit.

- *Individual family members will respond to a loss situation in different ways and may experience the impact of living with illness differently.*

  This assumption is supported by Kubler-Ross (1969) in her theory of loss and grief. It is also discussed by Shapiro (1994) who believes that family grief patterns may differ according to the variation of the illness. Kubler-Ross (1969) postulates that all family members negotiate certain stages of grief. Her theory showed that family members needed to express themselves openly and should be given an opportunity to talk about their varied reactions to grief.
Crisis such as a serious illness can be a transformative experience for family members and can lead to personal growth and learning.

Levington and Gruba-McCallister (1993) believe that one may regard the experience of suffering as providing one with a catalyst and impetus for ongoing spiritual, personal and interpersonal growth. Existentialist theorist Victor Frankl (1963) posited the search for meaning as a fundamental human need. As Frankl (1963) succinctly articulates, “suffering ceases to be suffering in some way at the moment it finds a meaning.” (p. 179).

In this chapter, the theoretical frameworks used in this study, namely ecological systems theory, structural family theory and grief and loss theories, were reviewed and related to the family coping with neurological illness. A section on research literature focused on the concept of illness as a traumatic event and explored the discovery of benefits from living with adversity. The study assumptions which resulted from the theoretical framework and research literature were presented. In the following chapter research methodology is discussed.
CHAPTER TWO: METHODOLOGY

INTRODUCTION

In this chapter, the research design, sampling procedure, data collection instruments, data collection procedures, limitations, ethical considerations, and data analysis methods are presented and described.

RESEARCH DESIGN

This study made use of a qualitative research methodology, so as to focus on the personal experiences of five individuals whose families lived with neurological illness. Cresswell (1998) defines qualitative research as “an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting.” (p. 15).

This study was phenomenological (Cresswell, 1998) as it provides a detailed description of the lived experiences of the participants. Moustakas (1994) conceptualizes a study as phenomenological if it searches for the essence of the experience and emphasizes inward consciousness which is based on memory, image and meaning. The phenomenological design provides an in-depth understanding of how individuals in a family cope with serious illness. It focuses on understanding the essence of four womens’ and one man’s varied experiences of living with illness and loss in their families. The
qualitative nature of this study empowers the participants to share their family stories and explores the underlying meanings of their experiences.

**SAMPLING PROCEDURE**

The target population of the study was adults who had a family member who was diagnosed and had lived with a neurological illness. The following inclusion criteria were used:

1. The participants were adults at the time of the study (i.e., had to be 18 years of age).

2. The participants had experienced living with a family member who had a neurological illness.

3. The participants spoke English fluently.

Purposeful sampling was used and five people from five different families were chosen. According to Maxwell (1996), purposeful sampling looks for particular people who have knowledge and experience relevant to the research question. Each of these individuals had experienced the phenomenon of living with a close family member who had a neurological illness. Each of the participants were involved in an in-depth semi-structured interview. Sandelowski (1995) writes that small sample size is adequate for phenomenological studies as they permit a case-oriented analysis that is hallmark of qualitative research.
A semi-structured interview guide was developed in order to collect the data from the interviews. The interview questions were based on the literature review (Chapter One), from the researcher’s previous experiences of interviewing families living with illness and loss, and in consultation with health care professionals at Vancouver General Hospital. The interview guide was pre-tested. Two individuals who had lived with serious illness in their families and a professional social worker were asked to comment on the relevance and clarity of the questions. As a result of the pre-test, the order of the questions was amended and some of the questions were modified.

The aim of the interview was to allow participants to tell their family stories in a sequence that they felt was comfortable and appropriate for them. The interview format allowed the researcher to acquire more specific information about the participants’ family experiences. The semi-structured format encouraged participants to share their stories and researcher bias was reduced due to the open-ended nature of the questions. The final interview guide can be found in Appendix A.

The interview questions were written according to the twelve aspects of an interview investigation as proposed by Kvale (1996, p.29). The questions were formulated according to the purpose of the investigation and aimed to explore the lived world of the participants and their relation in it. The questions then moved towards more depth and details of the participants’
family stories. Finally the questions explored specific situations and sequences in the participants’ experience of illness in the family.

**DATA COLLECTION PROCEDURES**

Two participants in the study were informally contacted through a synagogue group. The writer met them socially at a lecture on family experiences of illness and loss. These two participants approached the researcher after the group with an interest to participate in the study. The other three participants were introduced to the researcher by a work colleague who had discussed the proposed study with them. They expressed interest in participating in the study and were contacted by the researcher. Approval for the research was granted by the University of British Columbia (UBC) Behavioural Ethics Board. An introduction letter containing general information and explaining the purpose of the study as well as a consent form were given to participants. An appointed time for the interview was set up for each participant. Participants were offered a home interview or an interview in a public place. Four participants felt that an interview in their homes was more conducive to sharing. One participant was interviewed at a hospital close to her home. The interviews lasted between 60 and 120 minutes. All interviews were audio-taped and transcribed by a professional transcriber. All participants were assured their confidentiality would be respected and fictitious names were used. Participants were offered an opportunity to review and edit transcripts of their interviews and were informed that they would have access to the thesis results, upon request, at completion of the study. This
provided a means of checking for accuracy of description of their experiences and reduced threats to validity as proposed by Maxwell (1996). The semi-structured interview, as used in this study, had a sequence of themes to be covered, as well as suggested questions. The questions served as a general guide to ensure all relevant aspects were covered. At the same time there was flexibility to change the sequence and form of questions in order to follow up the answers given and the stories told by participants.

LIMITATIONS

Many features of this study have potential limitations that may affect the reliability, validity and generalizability of the findings. These limitations include:

1. The small size sample of this study may have led to key informant bias (Maxwell, 1996). The study investigator relied on a small number of participants for the data. There is no guarantee that the participants' views are typical or represent the diversity of experiences among families living with traumatic illness. For this reason, the study focused on developing insight and understanding in the area of the study, rather than attempting to generalize to the larger population.

2. Due to the small sample size of the study, cultural dimensions of families living with illness and loss were not adequately represented in this study. Due to the uni-lingual nature of the interviewer, personal interviews could
only be conducted in English and therefore cultural limitations were imposed on this study.

3. In qualitative interviews, the skills, style and characteristics of the interviewer play an important part in establishing the validity and reliability of results. The interviewer in this study has some experience in qualitative interviewing and has conducted qualitative interviews for two previous research studies. A validity check was carried out with all participants.

ETHICAL CONSIDERATIONS

Permission for this study was obtained from UBC Behavioural Ethics Board. Participants received an introduction letter outlining the purpose of the study and the nature and extent of their involvement. They were informed in writing that they may refuse to participate or withdraw from the study at any time, without consequence. Anonymity and confidentiality were maintained throughout the study. Fictitious names were used and computer information had a password protector.

Due to the sensitive nature of the interviews, one of the participants felt some transient emotional discomfort and was referred for ongoing support. Rosenblatt (1995) suggests that there may be ethical dilemmas related to discussing sensitive issues with participants. He strongly believes that “people who cry, fight back tears or express grief in some other way often seem afterward to be glad to have had a chance to talk about the issues that brought them to those feelings.” (p. 144).
DATA ANALYSIS

The intent of the analysis of this study was to focus on the narrative and extract the essence of the lived experiences of individuals. According to Coffey and Atkinson (1996), “the storied qualities of qualitative textual data, both ‘naturally’ given or research-driven, enable the analyst to consider both how social actors order and tell their experiences and why they remember and retell what they do.” (p. 57). The experiences of the participants could therefore be analyzed alongside meanings and motives. The analysis followed the steps to phenomenological inquiry outlined by Moustakas in Cresswell (1998). The steps are as follows:

1. The first step was to thoroughly read through the transcripts of the taped interviews and a line-by-line analysis was conducted.

2. The researcher then found statements in the interviews about how individuals were experiencing the topic and these were underlined and extracted from the transcript.

3. The statements were then grouped into “meaning units” or themes. Each theme was examined in terms of what was being said by the participant. This was written up as a textural description of the experience and verbatim examples were included. The choice of examples was influenced by the literature review and by the researcher’s previous social work experience.

4. After the themes were identified, related ideas were analyzed and compared in the thematic categories.
5. Finally, a synthesis of the themes and an overall description of the meaning and essence of the experience for each participant was written.

**SUMMARY**

In this chapter the methods used to describe the lived experiences of individuals coping with illness and loss in their families were discussed. This study made use of narrative analysis and followed the steps to phenomenological inquiry outlined by Moustakas (1994). The university Ethics Committee granted its approval to conduct the study. The sample consisted of four women and one man who had experienced neurological illness in their families. The participants were identified through a social network and met the inclusion criteria. The study was qualitative and based on semi-structured personal interviews. A semi-structured interview guide was designed by the researcher and used to collect relevant data for this study. Confidentiality of responses were maintained and participants were not mentioned by their real names.

In the chapter to follow the findings related to this study and their interpretation are presented and discussed.
CHAPTER THREE: PRESENTATION AND INTERPRETATION OF FINDINGS

INTRODUCTION

The study findings in this chapter are organized into three main sections. Section one provides a description of the five participants and a brief overview of their family stories. Next, the participants’ interviews and the study findings will be discussed around five emergent themes. Finally, the interpretation and meaning of the findings will be presented.

STUDY PARTICIPANTS

The characteristics of the five interviewees who gave in-depth personal interviews are summarized to provide a context in which to view each participant’s experience with illness and loss in their family. The participants were identified as Ally, Debbie, Dianna, Martin and Lisa.¹

Ally is a 31 year old woman who emigrated to Vancouver 3½ years ago. She is the youngest of four siblings and has two elder brothers. Her oldest brother lives in the U.K. and the younger one is married and lives in Vancouver. Her sister Rita was pregnant with her first child and living in South Africa and was diagnosed with Multiple Sclerosis (MS) in 1988.

¹ Not their real names. All names have been changed for reasons of confidentiality.
Initially, the family members were told that Rita had a mild form of MS and that she would go into remission for many years. The family was convinced that Rita would go on to lead a normal life. Unfortunately this never happened. Rita started having one attack after another and never really recovered from any of them. Rita had a small child at this time and Ally’s parents were involved in the care of her sister and her niece and have continued to be her niece’s caregivers. Rita was married at the time of her diagnosis and initially her husband was supportive; however, he was unable to cope with the devastation of her illness and Rita’s family became her primary caregivers. In 1995, surrounded by much love, Rita passed away. Her illness and death has had a profound impact on Ally as well as the other members of her family. In her poignant story, Ally described her feelings of pain and guilt as she told the story of her inner battles. These involved a need to face the reality of her sister’s illness, yet often this became too painful and Ally would retreat and run away from her pain and grief. Each person in Ally’s family experienced the pain differently. The love and support shared by this family and the courage and honesty shown by Ally while telling her family story are a true inspiration.

Debbie is a 46 year old woman, who has been married for over 25 years and lives with her husband John, in Vancouver. They have two sons aged 25 and 22. Three and a half years ago her younger son Pete had a motor vehicle accident which resulted in a spinal cord injury. Debbie recalled that fateful day and spoke about her feelings of utter helplessness. She was angry and confused and terrified that the doctors would not be able to save Pete’s life.
Pete has made an amazing recovery, is walking again and slowly returning to normal functioning. It was a long recovery process that presented the family with many challenges. Debbie's elder son, Paul, moved back to Vancouver at the time of the accident to be closer to his brother and to assist Pete in the recovery process. Debbie and John experienced relationship issues and Debbie told the story of how her anger separated them as a couple. They were able to reconnect around their pain and the family as a unit made remarkable changes in this healing process. Debbie and John were constantly supported by the love and strength of their family and friends and they believe that this support helped the family get through many trying times. In her story, Debbie talked candidly about her anger, pain and amazing courage to heal her son, herself and her family. Her depth of sharing and warmth made her family story deeply touching.

Dianna is a dynamic woman in her sixties who came from England with her young family to live in Canada in 1966. She is married and her two daughters both live in Vancouver. The year that she and her husband emigrated to Canada turned out to be a very stressful and trying one. Her elder daughter, who was nine years old at the time, was diagnosed with epilepsy. Dianna found herself in a strange new country with little support and this was a frightening experience for a young mother. Yet despite all her anxiety and grief, Dianna had enormous insight and was able to recognize that she needed to encourage her daughter to lead a normal life or her daughter would become socially and emotionally withdrawn. Her story is a story of courage and shows evidence of a mother's deep love for her child. Dianna was
determined that her daughter would not feel different from other children. In her interview, Dianna shared the joys and difficulties she has encountered over the years and the impact that her daughter’s diagnosis has had on her life.

Martin is a 44 year old man who grew up in an environment of wealth and privilege. As the youngest of three brothers he received a lot of attention from his mother and was a constant source of amusement to his father. In 1972, when Martin was 17, his father who was head of the family and greatly respected in the community had a devastating stroke that affected his speech. At first his father was not expected to live, but finally he pulled through and for the rest of his life, until his death in 1985, he had difficulties with communication and was unable to speak. Martin’s family story is filled with his love for his father whom he admired greatly. For many years he helped care for his dad and a strong bond formed between them. Unfortunately, his father’s illness precipitated a huge rift in the family and the family was torn apart, mainly over financial issues. In Martin’s poignant story, he explores his father’s illness and the impact it has had on his personal and family life.

When her children, a son and daughter, left home, Lisa was really enjoying her life. She was very involved in her church, had worked hard, had a great job and felt content in her marriage. All that changed in one terrifying moment almost three years ago when her son Chad was involved in a motor vehicle accident. At first Lisa was told his chances of survival were slim, but as the hours passed his chances of survival increased. Within a short time span, Lisa had uprooted her life from a small town in Northern British Columbia and
moved to Vancouver where her main focus was caring for her son. Her
strength and determination were commendable as she helped Chad make
remarkable steps forward in the healing process. Her son has an acquired
brain injury and was unable to communicate for many weeks. This remarkable
story of a mother's determination to succeed and the love that carried her there
is inspirational. Despite devastating personal consequences such as financial
difficulties and the eventual break-up of her 30 year marriage, Lisa was
somehow able to find the strength to start over and her son is presently living
independently in an apartment in Vancouver. The love and support shared by
Lisa and her children and the way they have succeeded against all odds are
truly amazing.

**DISCUSSION OF THEMES**

Whilst analyzing the data, five main themes emerged. The first theme
explores some of the **challenges** faced by participants at the onset of their
family member's illness and during its progression. Theme two focuses on the
**divisive reactions** of family members, which are tied to tensions in family
relationships. **Connective reactions** and supportive relationships encompass
the third theme of discussion. The fourth cites strategies used by participants
in coping with their experiences. It focuses on **adaptive behaviours** such as a
sense of humour, religion and faith and positive reframing. The fifth theme of
**growth and meaning** reports on participants construed benefits from their
adversity. Finally a therapeutic model towards healing explores the themes
and data presented.
**THEME ONE: CHALLENGES OF ONSET AND PROGRESSION**

This theme looks at the onset and progression of each participants' experiences with their family members' varied illnesses and focuses on some of the challenges they each had to face.

When Ally’s sister was diagnosed with M.S., her family was shocked, but still had hope that Rita would lead a normal life. The disease was supposed to have a gradual onset and cause little debilitation. The family was positive and felt that Rita would not experience any significant symptoms for some time. “Things kind of went on as normal, she wasn’t really debilitated and was getting on with her life and we were getting on with ours.” Unfortunately the disease took on a rapid progression. The family’s initial hope was replaced by despair, “... gradually she just started getting worse and worse and having one attack after another and never really recovering from any of them.”

Dianna had a similar type of experience with the onset of her daughter’s illness, yet the progression was different. When she was told the diagnosis was epilepsy she was shocked but immediately felt complete relief, “somehow instead of that being devastating it was rather a feeling of oh my God, she can live with that, I knew it wasn’t a killer.” Fortunately the disease was controllable through medication and some precautionary measures and her daughter has been able to lead a healthy and active lifestyle, “I feel so proud of what she has achieved and how she has overcome it...”
On that fateful day in 1995, Debbie recalled the trauma of her experience as she learned via phone that her younger son had been involved in a car accident. Debbie articulated her initial shock at hearing the bad news, "I just remember my heart beating so fast... I almost froze... I felt as if I couldn’t breathe... it was terrifying." Debbie reported feeling confused, overwhelmed and incoherent. “The rest is pretty much a blur in my mind... I remember the neurosurgeon saying that Pete was alive.” Over the next year and through many ups and downs Pete was able to make positive progress in his recovery process.

Lisa reported experiencing a similar reaction of shock to the devastating news of her son's accident. “The initial phone call came in the middle of the night and we were told he could possibly die before we got to the hospital. They told us if he survived 48 hours, each day his chances were better; I was devastated...” Both Lisa and Debbie, despite all the odds were able to see their sons make excellent progress over the next few years. Lisa recalls, “He worked through all that pain and never gave up. He was always very independent and very determined.”

Martin’s story also begins with the tragic news of his father’s stroke, “when he first had the stroke it was really severe, the doctors said that he wouldn’t live...” Miraculously, Martin’s father went on to lead a pretty active life despite his huge physical limitations. “At first it was clear he wouldn’t make it and we expected him to die; the fact is he went on for 15 years; the doctors couldn’t believe it.”
All participants experienced traumatic life events, yet the contrast is evident. For Ally and Dianna the onset of the disease was relatively hopeful and optimistic. For Lisa, Martin and Debbie it was filled with fear of death, grief and hopelessness.

The rapid progression of her sister’s disease was devastating for Ally. The other participants had a realization of survival and the emergence of hope for some form of recovery. For Debbie and Lisa there was also the recognition that the lengthy healing process was just beginning.

During the onset and progression of these illnesses, participants reported a need to keep balance in their lives. Balance, in particular, was necessary to face the tension between emotions and pragmatism. Two major areas of tension were identified under this theme: hope versus flight versus facing reality, and protection versus letting go.

**Hope vs. Flight vs. Facing Reality**

For Debbie and Lisa their sons’ survival was their most important initial focus. Once they both knew that their children had in fact survived, they were both faced with the uncertainty of long-term prognosis and expressed fear of the future; “I knew he was going to survive, I felt elated... but I was really frightened about what was around the corner...” Both these women reported walking the fine line between being hopeful and having to face the reality of their situations. “While Pete was in rehab we were over the worst, but beginning a long process of healing...”, “It’s a balancing act and it’s awful...”
because you don’t want to give up hope, but you also don’t want to have your head in the clouds and then end up being disappointed.”

For Martin his initial despair over his father’s stroke was replaced with hope for his survival. However, even after the family knew he would survive there were always questions about his father’s quality of life and fear of the future. “...throughout all those years I knew it could happen at any time, that he could just die at any moment...”

Ally recognized the importance of getting on with her life abroad and was encouraged to do so by her sister, yet she felt guilty and confused. “I remember not knowing if I should go or not. I felt a lot of guilt about leaving... I didn’t think I was doing the right thing by leaving... it was so hard, so hard...” Ally experienced immense pain about having to face Rita’s illness on a daily basis. “I couldn’t face it. I didn’t want to be there, I didn’t want to be around her.” But being away was worse and Ally was confronted by even more grief. “As soon as I left I felt terrible about having left and then I would go through this whole thing again.” Ally felt out of control, she felt lonely and isolated from her family. Then Ally realized that she was running away from herself and from her pain, and this became a turning point in her life. “I was just running from one place to another... but not realizing that I was taking myself with me and that’s what I was trying to run away from, was dealing with the illness.” At that stage Ally felt compelled to face the reality of her life. Finally, she realized that she had to resolve these issues within herself. She was forced to begin to deal with the reality of her sister’s rapid decline and imminent death. “So then
it finally came down to the fact of having to deal with the reality of it, that this had happened to us.”

Protection vs. Letting Go

For Dianna, her challenge came right after her daughter’s diagnosis. She knew that she had to allow her daughter to deal with her epilepsy without overprotecting her. The doctor’s words still echo in her head, “Her future is up to you, you can take this child home and turn her into an emotional cripple in a few days or you can let her live a normal life; it is up to you...”

A similar issue was brought forward by Lisa when her son had completed his rehabilitation and was determined to live in his own apartment. She reports having to walk the fine line between protecting him from the outside world and accepting that she had to let him go. Both parents faced similar challenges. “It was so hard knowing what the world out there is like and wanting to protect your child from that. But I also knew I had to try to let go and it was hard...”

Theme Two: Tensions in Family Relationships – Divisive Reactions

Throughout all five participants’ stories, reactions of different members wreaked havoc on the family relationships and were seen as disconnecting forces. Debbie needed someone to acknowledge her anger and felt isolated from her husband. “I wanted him to recognize my anger and acknowledge it, not criticize it, and at that point it really did cause a rift in our marriage.”
John internalized his pain and his way of coping angered Debbie. Looking back she recognized, “you know we each had our own ways of dealing with our sadness and pain. I really felt as if we were disconnected from each other.”

Lisa’s experience has some similarities to Debbie’s in that her son’s illness “basically just turned our lives upside down” and led to the eventual break-up of her marriage. “My husband didn’t cope very well with the accident, he escaped at first into his work and buried himself in it. He couldn’t cope and just walked away.” For Lisa this was devastating and she commented that “unfortunately our family didn’t survive.” She felt that she and her husband “dealt with it separately, never together.”

For Martin, his father’s illness initially brought the family together but then precipitated a break up. Martin watched as his family was torn apart by greed when his father was unable to hold the family together. “It brought us together for a while, but then eventually it totally split us apart... and yes...I definitely felt angry about it.”

Ally’s story is also filled with pain and anger. “You know at times I felt so angry, why was this happening to our family, and then I felt bad for blaming, so bad for everything.” As Rita’s illness progressed, the pain for Ally became almost unbearable. “She wasn’t my sister anymore, this was a different person... I remember discussing this with my brother and we would both just cry.” It became evident that Ally had lost the companionship of her sister, long before Rita died.
Dianna’s grief made her feel separated from her family and her pain was in a sense an alienating force. She believes that her and her husband expressed their pain in different ways, “We tried to support each other and we did in many ways but what I realized was that when you grieve you grieve alone and neither of us could assist the other one because we were both involved in our own grief, you know.”

Four of the five participants saw anger and pain as potential alienating forces in their family relationships.

**THEME THREE: SUPPORT IN FAMILY RELATIONSHIPS – CONNECTIVE REACTIONS**

In all five participants’ stories their family members took on different roles and there was evidence of family connection, at least among certain members of the family. This was emphasized by Ally’s comment “I guess it was just the realization that we needed each other, that nobody could do it on their own... in unity there is strength, you know everybody needed everybody else to lean on, to cry to, and everybody was kind of trying to help everybody else.” Ally was able to connect with her older brother and found someone to acknowledge and share her pain. Ally’s mom was overcome by her pain and grief and was unable to talk about it. Ally’s father was not a very verbal person and although he did not voice his feelings, he was deeply saddened by his

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2 The term family is used to incorporate extended family and close friends.
daughter’s illness. Ally’s father and younger brother were able to assist with instrumental help. Ally recalled, “My father and younger brother kind of got down to the business of doing the practical things, building ramps or a special lift for the car, they would do all that.” Perhaps the heroine of Ally’s story is her niece, who despite her young age gave her mother unconditional love and unconditional acceptance. “From the youngest age she was this accepting little girl who only wanted to ever help and be there for her mom. It used to break our hearts to see this little child helping her mother put on her shoes; the roles were reversed.” Ally’s story also revealed evidence of outside support and assistance. Ally recalled the multi-faceted nature of her adaptation. Rita’s illness was not just a spiritual loss or a physical loss for herself or her family. The loss affected her in many dimensions of her life. “This sort of experience really tests you to the total limits, um, emotionally, physically and spiritually, um, in all spheres of your life.”

For Martin, the experience of his father’s stroke definitely strengthened the bond between him and his parents. “It brought me closer to my mom and my dad... I really got to know my dad and I remember my mother saying to me, ‘you are the one who really cares about me’.” There were close friends of the family whom he remembered as being warm and supportive. “There was a group of people that were around my dad, that were there forever. They became my best friends and were loyal to my dad. I was really close to them... yes they were always there as far back as I can remember.”
Debbie reported a strong sense of family solidarity and family unity. “It was so great to be a family unit and be together again to face this, you know, I realized how we counted on each other and how important we were for each other.” She continues, “Paul was and is very close to his brother and has hardly left Pete’s side since the accident. They love each other and it was this kind of courage and love that kept me going.” It appears that this strength of connection and support provided by Debbie’s family and friends contributed greatly to the healing process. “There were so many people who were a constant source of support, our family and friends were so wonderful, I don’t know... how I could have done it without them.” Without this wonderful support system, Debbie felt that she “may have fallen apart.”

Lisa’s children were close before the accident and they have continued to maintain this kind of relationship. “It was hard for my daughter, but she is very involved with Chad and she has demonstrated her abilities... and they are close, they always got along.” Lisa got amazing support from her friends and extended family and felt encompassed by the warmth offered by her community. “We both grew up in Vancouver, so we had all of our family here and many good friends.” Her son’s friends also visited the hospital daily and Lisa remembers, “we were really close to his friends and in that way it was a positive experience.”

When Dianna’s daughter was diagnosed, her family had only lived in Canada for three months and knew few people. Yet despite this fact, Dianna remembers their care and concern. “At the beginning we didn’t have many
friends. We did have neighbours who became our friends and they were incredibly supportive.” Dianna remembers how her parents, although far away in England, reacted to her daughter’s diagnosis with care and concern, “they were open to talk about it and very supportive.” She recalls that her daughters also shared much love and supported each other.

**Theme Four: Adaptive Behaviours and Strategies**

Adaptation strategies cited by participants include a sense of humour, religion and faith and positive reframing.

**Sense of Humour**

Both Debbie and Ally described a sense of humour as a coping mechanism. Debbie described the use of humour in her family as a connecting experience, “the one thing that really strengthened our bonds was a good sense of humour. You know, it isn’t about laughing at people, but rather laughing at situations and this comic relief definitely bonded us as a family.” Ally believed that laughter was a great release for her pain. “At times I didn’t know whether to laugh or cry... humour, I guess was just a better option...”

Lisa reported that despite her son’s physical limitations and limited capacity for communication, his sense of humour continued to shine through and was a positive inspiration. “His humour was still there and he even played jokes on us...one day I asked him if he was pulling my leg and we got a breathy laugh...”
Religion and Faith

Debbie's story shows how prayer and religion became a source of strength for her. "I started to develop a relationship with God and I found that I prayed so hard and found a lot of solace from my prayers." Prayer became a tool of adaptation that has assisted Debbie greatly over the past few years.

Lisa was very involved in her church community and spoke about her strong faith in God. She believes this faith gave her the ability to continue through the difficult times. "I guess the whole experience, it strengthened my faith, at first I thought why are all these things happening. I think there is a reason for everything. I believe we all have a purpose, so everyday he survived, I thought, okay, why would God let him survive this long – after a week, I decided, I just thought I can’t give up, there is a purpose for this...”

Positive Reframing

All these stories brought to light some form of personal growth. For Martin this involved “Seeing life from a different perspective...looking for the positives...” All participants felt meaning had been extracted from their painful circumstances and some form of learning had taken place. For Ally it was the realization that “However terrible it is there are some positives, in all the terrible negative things that happen, you have to find the positives and you have to just use it as a learning experience, use it as something that will enrich your life.”
THEME FIVE: GROWTH AND MEANING

Most participants reported an enhanced philosophical view on life. For Ally, her sister’s illness was “like an eye-opener into being a better person, a person more able to cope with anything life throws at you.” For Debbie, her son’s accident was shocking, but she felt that “no matter how terrible the situation or how devastating it is for the family, there are always good things that come out of it.”

Appreciation

Dianna’s experience made her grateful for “the smaller things in life” and she was careful “not to take things for granted.” Some participants expressed a deeper appreciation of others, especially their families. For Debbie, this involved “taking less for granted. Everyday that I am surrounded by my family, I feel so lucky, I really do.”

Self-Exploration and Self-Discovery

Lisa and Debbie both felt that their sons’ accidents had provided them with an opportunity for personal growth and self-discovery. “I learned a lot about me, I was almost forced to face myself and sometimes that was the most difficult thing.”

For Ally, Rita’s illness and death propelled her into a journey of self-exploration. “It prompted me to explore more about my feelings and, you
know, just my life in general. I feel that I want to understand things more and I guess be in control of my emotions and destiny.”

**Compassion**

For Martin, living with his father after his stroke taught him a great deal about compassion and caring. “Caring for my father definitely helped develop my sense of compassion and I think I just continued to develop it...” Debbie also reported a lot more empathy due to this experience, “I felt as if I could really understand another parent’s pain...”

**Altruism**

Lisa said that she felt a need to help others in similar situations and that this experience had even prompted a possible change in her career. “I would really like to help other people, especially those who don’t have the support system.” Debbie also felt ready to reach out to others experiencing this kind of situation. “I’m starting to feel like I could help others and would like to do some volunteer work.”
Figure 1: Towards a therapeutic model of healing

Challenges of Onset and Progression
- Hope vs. flight vs. facing reality
- Protection vs. letting go

Tensions in Family Relationships
- Divisive reactions

CYCLE OF LOSS

CYCLE OF HEALING

Growth and Meaning
- Appreciation
- Self-exploration & self-discovery
- Compassion
- Altruism

Adaptive Behaviours & Strategies
- Sense of humour
- Religion and faith
- Positive reframing

Support in Family Relationships
- Connective reactions
INTERPRETATION OF FINDINGS

Whilst interpreting the interview findings, emergent themes were organized into two cycles, the cycle of loss and the cycle of healing. Interpretation of the findings will be discussed around these two cycles.

The *therapeutic model of healing* as described in Figure 1 represents the data collected in the five interviews and is backed up by some current literature. This model reflects two cycles that participants experienced during and after their family members’ illness. The first cycle has been termed the Cycle of Loss and has a common theme of loss and grief running through it. Participants’ experiences in regards to their pain, anger and challenges they had to face have been recorded in this cycle. For much of the interviews, participants spoke of family tension and the divisive reactions they had all experienced in varied ways. When they had discussed details of their pain, anger and grief, I found that they spoke of the processes of healing that took place in their lives. Thus the next few themes have been called the Cycle of Healing. Within this cycle participants shared evidence of connective family relationships, personal triumphs and for some the paths of self-discovery they had embarked upon. The arrows reflect the fluidity of the cycles and show that this is a spiraling and ongoing process. Participants who experienced personal triumphs and connective family relationships may still have to go back to rework issues in the cycle of loss and vice versa. I have labeled this process *Towards a Therapeutic Model of Healing*, as participants shared that they felt it was necessary to explore their pain and grief (cycle of loss), in order to begin to
experience a sense of appreciation, connection and in some cases, compassion (cycle of healing).

**THE CYCLE OF LOSS**

The cycle of loss is a cycle in which people experiencing traumatic events in their lives are given the opportunity to experience the emotions surrounding their pain and grief. The cycle of loss has grief at its nucleus and explores the differing emotions associated with pain. Pain can be a healing emotion and can present an opportunity for connection, however, it can also cause separation and withdrawal. Freeman's concepts (1998) of "sadness of the soul" and "pain as a sacred emotion" embody the quintessence of this cycle.

**Challenges of Onset and Progression**

A central theme was that of acknowledging the sadness and pain that is associated with coping with illness. All participants in the study articulated feelings of both fear and hope and acknowledged that emotional pain was a daily experience. One participant dealt with her pain by running away and for some participants, their pain was channeled into hope and prayer for their family member's recovery. All interviewees found themselves facing differing challenges as they coped with their feelings of loss and grief each day.
Tensions in Family Relationships – Divisive Reactions

It became evident that experiencing pain could be both a connecting and a separating experience. For some participants there was much evidence of separation around painful issues. Anger and pain seemed to be interconnected and linked. Freeman (1998) proposes the idea that pain and anger are the same emotion. Pain is often the internalized expression and anger could be the externalized expression. Some participants found that although their anger was cathartic it became a disconnecting force in their relationships.

THE CYCLE OF HEALING

When participants had been given the opportunity to discuss the enormity of their pain and grief, then they spoke about their experiences of healing. This cycle has the powerful images of support, connection and growth at its core.

Support in Family Relationships – Connective Reactions

Some participants viewed pain as a connecting force and reported that their common pain and grief promoted connection and bonding in their relationships. Four participants experienced a deep connection around pain with their siblings and/or other members of their extended families. This is the core of Freeman’s theory (1998) of pain as a sacred emotion, that can bring people together and help them make meaning out of traumatic experiences.
The strength of family connection was highlighted throughout all interviews. All participants engaged in healing relationships with some of their family members or extended family and positive connections were reinforced. For all participants these positive connections promoted acknowledgement and bonding. Therefore, the importance of relationships in the healing process cannot be overemphasized. Freeman (1998) introduces the notion of being a safe witness. This is the idea that family members are given the opportunity to share their family stories in a safe environment, with a solid person who is able to listen to and validate them.

**Adaptive Behaviours and Strategies**

Three participants believed that their coping abilities were strengthened through the use of humour. Two participants reported on the importance of religion and faith as coping mechanisms in their adversity. Other participants felt there had been some positive aspects brought about by their experiences and positive reframing was cited as an adaptive strategy.

**Growth and Meaning**

Evidence that crisis can be a transformative experience was clearly disclosed by all participants. Some spoke about the personal growth and meaning they took away from their experiences. What emerged from one interview was the fact that learning through experience is a solid type of learning. Two participants expressed the need to reach out to others in similar situations and experienced forms of personal transformation. Some
participants embarked on journeys of self-exploration and discovered new things about themselves and their families.

Tedeschi and Calhoun (1996) postulate that one class of benefits cited by individuals who have faced difficult experiences is positive changes in perception of self. Three participants revealed that crisis can stimulate positive shifts in life-perspective and improve self-concept. Taylor (1983) believes that when people experience personal tragedies, their adaptation may include a search for meaning in the experience, an effort to regain a sense of mastery, and an attempt to restore a positive sense of self.

All participants believed that this experience had given them an opportunity for growth and meaning in their lives. For some this meant a greater appreciation of their families, for others an increased sense of compassion and empathy.

In the concluding chapter, an overview of the study is presented followed by the conclusion, implications for social work practice and policy, and recommendations for further research.
CHAPTER FOUR: SUMMARY, CONCLUSION, IMPLICATIONS AND RECOMMENDATIONS

INTRODUCTION

"Life is filled with loss. It is inevitable in the experience of living. It is inescapable, yet necessary for growth." (Arnold & Gemma, 1994, p.3).

This study was designed to explore the ways in which five individuals were able to cope with a family member who had a neurological illness. In addition its purpose was to gain more insight into their personal experiences and explore the unique ways in which they adapted to their illness, loss and grief. This study enabled the researcher to gain a deeper understanding of individual and family reactions to illness from the perspective of five family members. It documented the ability of individuals to heal their pain and their determination and courage to move forward in the face of adversity. An overview of this study is presented in this chapter followed by the conclusion, implications for social work practice and policy and recommendations for further research.

SUMMARY

This study gave voice to the profound personal experiences of four women and one man whose families had experienced neurological illness. I have worked with families in a hospital setting for the past eight years and have always been amazed at the varied ways families are able to deal with
illness. For some families, living with illness strengthens their connections, for others, it causes painful separations. Families living with neurological illness live also with much pain and grief. Some family members are able to beat the odds and overcome their difficulties, whilst others remain bitter and filled with anger and pain. It has always interested me how some people are able to face adversity and bring healing and meaning into their lives.

In order to explore all these varied reactions the study made use of a qualitative research inquiry to focus on the personal experiences of five individuals. The target population of this study was adults who had a family member who was diagnosed and had lived with a neurological illness. The participants included a woman whose sister had Multiple Sclerosis; two mothers whose sons had been diagnosed with a spinal cord injury and an acquired brain injury after motor vehicle accidents; a man whose father had suffered a severe stroke and continued to live without being able to speak for 15 years and a woman whose daughter had been diagnosed with epilepsy, shortly after the family had emigrated to Canada.

A semi-structured interview guide was developed in order to collect the data from the interviews. The interview guide can be found in Appendix A. Participants were interviewed individually and interviews lasted between 60 and 120 minutes.

During the interviews five themes emerged. They included a review of the onset and progression of illness in each participant’s situation and explored some of the challenges participants faced in this process. The second theme
delved into tensions in family relationships and focused on divisive reactions of family members. Theme three focused on supportive family relationships and connective reactions. In the fourth theme participants discussed some of the adaptive behaviours and strategies they employed during their experiences such as positive reframing, humour and religion and faith. Finally it became evident that all participants had emerged from their experiences with differing forms of appreciation, compassion and self-knowledge. The fifth theme encompassed participants’ experiences which were meaningful for them.

**CONCLUSIONS**

The themes that emerged from the study were grouped into two cycles, namely the cycle of loss and the cycle of healing. The first two themes were incorporated into the cycle of loss and explored many painful issues brought up by the interviewees. The last three themes were incorporated into the cycle of healing and these themes focused on supportive relationships and personal growth. It became evident that participants first needed to explore the enormity of their pain and grief and then they were able to focus on the positive and more healing aspects of their experiences.

An exploration of the literature on coping with adversity shows evidence of both similarities and differences with the findings of this study. One of the main findings is the recognition that illness involves all members of the family. Ell and Northen (1990) back this up by stating that the overall management of and response to illness is increasingly recognized as a family affair.
One of the challenges faced by participants was hope versus flight versus facing reality. In this study flight was symbolic of feelings of isolation and avoidance. Wethington and Kessler (1991) cite avoidance as one possible coping strategy. This is not consistent with the findings of this study as avoidance or flight was seen as a challenge rather than a strategy relevant to coping.

An emergent theme of this study focuses on tensions in family relationships and divisive reactions of family members due to serious illness. Baltrusch and Waltz (1986) support this and believe that differing coping styles of individual family members can cause feelings of isolation and separation. These feelings were also reported by participants in this study.

Once participants had spoken about their pain and grief they then shared some of their positive experiences brought about by the illness of their family member. Ell, Mantel and Hamovitch (1988) conducted a study which demonstrates the value of examining both positive and negative feeling states when studying adaptation to illness.

Another major finding of this study shows evidence of family connection. This is reinforced by Ell (1984) who believes that there is convincing evidence that family support enhances recovery and rehabilitation outcomes. Cobb (1976) states that support from significant others can enhance adjustment to illness. There is strong evidence of this throughout the study.

Some participants reported an increase in their religious faith and sense of purpose. This is similar to Janoff-Bulman's (1992) findings and research
conducted by Yalom (1980). However, this is not consistent with McCrea's finding that religion is most used and useful for those who experience illness or death of a loved one. Participants found that some positive aspects had been experienced due to their illness and this finding is supported by Tedeschi and Calhoun (1995) and Taylor and Armor (1996). Finally, all participants identified the development of personal growth and meaning as a result of their experiences. This finding is also confirmed by Debats (1996) and by Jaffe (1985).

It is important to assess how social work practitioners could intervene with families in order to reinforce positive connections and decrease divisive reactions of family members. Ell and Northen (1990) suggest that social workers can reinforce connective relationships in families by assisting them in developing effective communication and problem-solving skills. They also believe that families should be helped with the utilization of appropriate resources in order to cope successfully with serious illness. This study found that increased family connection was a top priority for most participants whereas resource development was seen as a lower priority.

**Implications**

Implications for social work practice are discussed in the following section. An overview of hospital policies and some of the new directions in health care in Canada will then be reviewed.
Social Work Practice

There are many models of family therapy and a wide divergence of opinion regarding the role of social work practice with families. I believe that the models we as social workers use are shaped by the experiences and exchanges we have had with our own family. Our practice values and beliefs are drawn from our own poignant and painful family experiences. How we as practitioners understand and approach families will also be sharply influenced by the emotional work and healing we have accomplished on a personal level. As a result of this study seven important implications for social work practice have emerged.

I would like to emphasize the importance of a healing component in any family therapy model. This is supported by the finding of this study that connective relationships are important in the healing process. It is my strong belief that family therapy models must be about embracing, about connection and about belief in self and others.

When tensions in family relationships emerged, participants spoke about their feelings of isolation and lack of acknowledgement. The next two implications, namely listening and acknowledging pain cannot be overemphasized.

Listening is about a deep appreciation of emotion. The more we listen, the more validated our clients feel. This involves staying with the client’s intense feelings of grief and the ability to embrace their deepest fears and anxieties. Social workers may be uncomfortable with the depth of emotion
expressed by their clients and their feelings of helplessness may mirror those of their clients. It is important to listen without judgement, or rather to be aware of our judgements and reactivity levels. Often, I am touched by the privilege I have as a social worker, the privilege of being part of another human being’s deepest emotional state.

Modern society is so fixated on diagnosing and curing pain that the healing properties of pain are often disregarded and distanced from people’s consciousness. I believe an essential component for effective practice is the ability to **acknowledge and stay with pain**. We need to set up a safe environment for our clients to express their pain. I believe that pain can be an opportunity for connection. I have seen that when some people are able to acknowledge and embrace their pain, the healing process truly begins. In this study it was found that once participants spoke of their pain and grief then they were ready to explore positive aspects of their experiences. The cycles of loss and healing (Chapter Three) expand upon this concept. It is my strong belief that social workers who are unable to connect with their client’s pain, may also have difficulty in assisting their clients in the healing process.

Another implication for social work practice is the **acknowledgement of the power of relationships**. I believe that it is important to have a relationship to heal. All participants spoke about the importance of supportive relationships. When families are in crisis, all they often need is to feel human presence and acceptance. Social workers, family members and other
caregivers should not underestimate this important role: the power of being there for another person, in silence, in joy and in pain.

There is much research that suggests that individuals are able to find meaning from experiences such as serious illness (Baures, 1996; Debats, 1996; Tedeschi & Calhoun, 1996). I also believe that crisis situations can present us with opportunities for personal growth. This was supported by a finding in the study which showed that all participants had found some form of meaning from their experiences. As practitioners we should recognize that serious illness in a family can be an **invitation to healing and building meaning**. Frankl (1963) maintained that in order to survive individuals need to derive meaning from their suffering. Another implication for social work practice encompasses one of my research findings that shows that living with illness and loss can be a **transformative experience** that helps individuals to gain a greater sense of appreciation and compassion.

Altruism emerged as another finding of this study. While working with families who are coping with illness, I have also noted that when people gain courage and strength within themselves, a true measure of their healing is in their ability to **reach out to others in similar situations**. I believe that this can be a positive way in which people’s pain can be channeled into meaning and insight.
Hospital Policy

The findings of this study support the current policy of care at the Neurosciences Unit of Vancouver General Hospital (V.G.H.).

The Neurosciences Unit at V.G.H. is the centre of excellence for all neurological traumas in British Columbia. V.G.H. has embarked on a vision of "patient-focused" care in an effort to improve its effectiveness. In the hospital's vision statement (see Appendix D), it stresses that V.G.H. strives "to create a patient-focused" academic health science centre where staff and volunteers are committed to fostering an environment that places the needs of our patients and their families above all other concerns." Hospital policy emphasizes that "service delivery, leadership style, information and resources will all be structured around the needs of our patients."

These new directions in health care place the patients and their families at the centre of all health care activities and focus on psycho-social aspects of patient care. This is important as it links to a major finding of this study namely, the importance of family ties. More traditional approaches in health care have failed to recognize the importance of this combination for effective patient care. Traditional models focused mainly on patients' medical problems and therefore for hospitals to be taking these new initiatives and recognizing their importance is of major significance. Patients and their families are consumers and should be regarded as essential components in the decision-making process. This study found that most participants felt shocked and overwhelmed at the onset of their family member's illness. V.G.H.'s patient-
focused policy could assist families in developing support networks. It could also increase adaptive behaviours as it would reinforce a sense of inclusion and control for the family. The question remains: should the hospital be involved in the life of people outside of the hospital? The answer is an unequivocal yes. Most health care professionals are in favour of this involvement; however, financial constraints and budget control over health care programs, such as Continuing Care, place this caregiving burden solely on the family. Findings in this study show that the family is already overloaded with their pain and grief and this further adds to their tension and stress.

Hospital policy is recognizing the importance of effective discharge planning and the integration of community resources. This brings to light a major implication of this study: the importance of providing services that are not only patient-focused but family-focused. This increases connection and support for both the patient and their family members. One of V.G.H.'s seven dimensions of Patient-Centred Care (see Appendix E) is transition and continuity. The next section discusses this important dimension in regard to Public Policy.

Public Policy

Public policy directs the allocation of resources that patients with neurological illness require. One of the more challenging roles of social work is to bridge the gap between patient needs and health care policies. This includes assisting families in fostering connective relationships and utilization of resources which has already been discussed. This also involves advocating for
our patients on a personal, hospital and public level. This can sometimes seem a rather daunting task. Most patients who have a neurological illness such as an acquired brain injury or a stroke have all their medical costs covered by the Medical Services Plan (MSP), Insurance Corporation of British Columbia (ICBC) or the Workers' Compensation Board (WCB), depending on the nature and onset of their illness. Most patients are offered rehabilitation which is also covered and some receive up to four hours a day of homemaking and other community services through Long Term Care. For many patients their problems begin once they have completed their rehabilitation and are unable to live independently in their communities. At this point there is a huge lack of resources, especially for the younger patients. Young adults are often sent to Extended Care Units which are highly unsuitable for their needs due in part to their age and also their high level of care needs. For patients who are able to go home, the Continuing Care program offers them a maximum of four hours of personal care per day and families are left with the main caregiving responsibilities. This places a huge strain on the family members, who have already faced major upheaval due to one member’s illness. Patients are often brought back into the hospital in crisis due to their limited resources and the cycle begins again. Findings of this study have shown that lack of support can increase tensions in family relationships. As social workers, it is our role to assess families’ coping strategies and to increase their problem-solving and decision-making skills. We need to advocate for our patients while they are in hospital and assist in setting up effective discharge plans. We also need to be lobbying on a broader level so that health care policies recognize the gaps in
the system and new services and resources are set up within the community. Intervention should take place not only at a micro and meso level but also at an exosystem level. Finally, we cannot overemphasize the important role families play in health and illness and the important role social workers play in focusing on family-centred practice.

**Recommendations for Future Research**

The findings, conclusions and implications highlighted in this study form the basis for future research. It is my hope that this study elicits the interest of other health care professionals and assists them in their work with families.

This study relied on information from a small sample size and all interviews were conducted in English. It would therefore be interesting to replicate this study with a larger sample size from various cultural groups in order to broaden generalizations and implications. Varied cultural perspectives in dealing with illness and loss would be of particular interest.

It may be beneficial to conduct interviews with all the members of a family living with neurological illness and loss. A comparative study of each family member’s experience would be valuable. A multigenerational study of families living with illness and loss exploring the ways in which grief and healing patterns are passed down across generations would be of particular interest.

Due to some of the implications of hospital and public policy discussed in this study, further research is required in this area. It would be interesting
to assess how new directions in hospital policies have impacted on the care of patients after their acute hospital stay. It is my hope that further investigation is pursued in these areas particularly in the area of people's coping abilities in the face of adversity and suffering.
REFERENCES


APPENDIX A

Sample Interview Questions
APPENDIX A – SAMPLE INTERVIEW QUESTIONS

1. Can you tell me about your personal experiences of living with a family member with a neurological illness?

2. How has this experience impacted on your life?

3. How was your family before this experience?

4. Who in your family was able to help you through difficult times?

5. Have other family members' ways of coping with this experience influenced the way you have dealt with it?

6. In your opinion, how has your family been able to pull together and strengthen their bonds?

7. Tell me about the positive aspects of this experience.

8. Is there anything else you would like to share about your experiences?

9. How has this interview been for you? Please share your thoughts and comments.
APPENDIX B

Introduction Letter
APPENDIX B – INTRODUCTION LETTER

November, 1997

Dear family member:

My name is Dee Fittinghoff. I am a Master of Social Work student at the University of British Columbia.

As part of my studies, I am interested in learning more about the impact of neurological illness on the family. I am especially interested in looking at how the family is able to live with pain and grief. It is my hope that this study will promote an understanding of the different ways in which individual members of a family are able to deal with illness and loss.

Participation in this study would involve a 1-2 hour audio-taped interview with myself, at a location convenient to you. This interview will be held early in 1998. Sample interview questions and a consent form will be given to you beforehand. A follow-up meeting may also be requested.
APPENDIX C

Informed Consent Form
APPENDIX D

Vancouver General Hospital
Vision Statement
VISION STATEMENT

At Vancouver Hospital & Health Sciences Centre, people are dedicated to helping people. Our strengths lie in the skills and talents of our staff and volunteers, the quality and efficiency of our services, and the scope of our teaching research.

The mission of Vancouver Hospital and Health Sciences Centre, as the major health care partner of the University of British Columbia, is to create a Patient-focused Academic Health Sciences Centre where staff and volunteers are committed to fostering an environment that places the needs of our patients and their families above all other concerns.

The terms “patient-focused” and “academic” best describe the essence of our plans for the future. Service delivery, leadership style, information and resources will all be structured around the needs of our patients. Teaching and research will be an integral part of the hospital and will complement the patient services we provide. By taking new knowledge and applying it to what we do, we can improve the care provided, both for our patients of today and the public of tomorrow.
APPENDIX E

Vancouver General Hospital:
The Seven Dimensions of Patient-Centred Care
APPENDIX E – VANCOUVER GENERAL HOSPITAL: THE SEVEN DIMENSIONS OF PATIENT-CENTRED CARE

The Seven Dimensions of Patient-Centred Care

... Through the Patients’ Eyes