

Understanding The Suffering Of The Family Members
Of People With Mental Illness

by

Wilhelmina Maria van Wiltenburg
BSN, University of Victoria, 1996

A Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF NURSING

© Wilhelmina Maria van Wiltenburg
University of Victoria

All rights reserved. This thesis may not be reproduced in whole or in part, by
photocopy or other means, without permission of the author.

Understanding The Suffering Of The Family Members
Of People With Mental Illness

by

Wilhelmina Maria van Wiltenburg
BSN, University of Victoria, 1996

Supervisory Committee

Dr. Carol McDonald, Supervisor
(Department of Nursing)

Dr. Anne Bruce, Departmental Member
(Department of Nursing)

Dr. Jane Milliken, Departmental Member
(Department of Nursing)

Supervisory Committee

Dr. Carol McDonald, Supervisor
(Department of Nursing)

Dr. Anne Bruce, Departmental Member
(Department of Nursing)

Dr. Jane Milliken, Departmental Member
(Department of Nursing)

ABSTRACT

The aim of this research is to increase our understanding of the suffering of the families of people with mental illness. I am exploring this phenomena from a hermeneutical perspective. This approach lends itself to moving back and forth from the present to the historical and through extensive examination and interpretation of text uncovers new meaning. Through rigorous interaction of current and past literature and in depth interviews of several family members this study found that family members with an mentally ill relative experience intense, pervasive and relentless suffering. The descriptors family members use to describe their lived experience include the following: lost, unsuspecting, disconnected, unbearable, betrayed, guilty, forsaken, reproach, torture, terrified, grief, misunderstood, pervasive, hopelessness and transforming.

Table of Contents

	Page
Thesis committee	ii
Abstract	iii
Table of contents	iv
Acknowledgements	v
Dedication.....	vi
Chapter 1. Coming to the Question	
i. Introduction	1
ii. Origins of the Question	1
iii My Personal Experience	3
iv. My Professional Experience	4
iii. The Research Question	6
Chapter 2. Significance of the Research	8
Chapter 3. Conceptualizing the Landscape.....	12
i. Mental Illness	12
ii. Family.....	14
iii. Suffering	16
Chapter 4. Approach to inquiry	18
i. Researcher as Instrument	19
ii. Participant Group (Sample)	20
iii. Participants	22
iv. Interviews	23

v. Interpretation	25
vi. Appraisal	26
Chapter 5. Ethical Considerations	28
Chapter 6. Expanded Understanding	32
i. Recognizing Mental Illness.....	32
Lost	32
Unsuspecting	32
Conflicted	32
Disconnected	33
ii. Day-to-day Management of the Illness	34
Unbearable	34
Betrayal	34
Guilt	35
Forsaken	36
Reproach	37
Torture	37
Terrified	39
iii. The Long-Term Care and Support Phase	40
Pervasive	40
Misunderstood	40
Grief	41
Hopelessness	42
Transforming	44

Chapter 7. Conclusions	45
i. Effect of Research on the Researcher	45
ii. Implications for Practice	47
iii. References	51
iv. Appendixes	58

Acknowledgements

I would like to extend my heartfelt appreciation to all those who supported me in this work coming to fruition.

First, my deepest gratitude goes to the family members that gave me a wonderful gift; their stories. We have walked ever so briefly together and I thank-you for sharing of yourselves.

Second, I am forever grateful to my family and friends for their unwavering support. To my devoted husband, Jack, my amazing children, Jonathan & Jenna, Anna & Drew, Jaclyn & Steve and Erin, thank-you for interest, encouragement and patience. To my very dedicated friend Tina, thank-you for hearing me over and over and over again.

Third, to Carol McDonald my remarkable supervisor, your guidance was invaluable. Thank-you for your confidence in my ability to engage this work. To Anne Bruce, Jane Milliken and Pat Mackenzie, thank-you so very much for your support.

Finally, to Camosun College, thank-you ever so much for the time and financial support you have given me.

Dedication

This work is dedicated to

Anne Bowles,

for her passionate commitment to the care of families dealing with mental illness.

Introduction

The World Health Organization (WHO) states that one in four people suffer mental illness (WHO, 2004). This could mean that in Canada 25 % of people and their families have been affected by mental illness at least once in their life. It is estimated that about 16% of health care expenditures can be attributed to psychiatric disorders, thus, in Canada, this places mental illness amongst the most costly of all conditions (Joubert & Stephens, 2001). Mental illness has a pervasive effect on an individual's day-to-day life; for individuals with mental illness and their families, the costs are incalculable.

Care of individuals suffering from mental illness has historically been given low priority (Pomeroy, Trainor & Pape, 2001; Sareen, Cox, Afifi, Yu & Stein, 2005). Research regarding mental illness has been treated with indifference and has been chronically under-funded. Service provisions for individuals suffering with mental illness and especially their families are sparse, and those that do exist are fragmented; ideologies of 'deservedness' and 'scarcity' appear prevalent. Equitable relationships between families and mental health care providers are reportedly rare (Spaniol, Zippie, Marsh & Finley, 2000). Deinstitutionalization, the down sizing and the restructuring of mental health services, have resulted in significant burden for the families of the mentally ill (Lefley, 1987). It is the suffering of families of people with mental illness that is of interest to me in this research.

Origins of the Question

There is an abundant amount of research on the family experience of living with mental illness (Saunders, 2003; Marsh, 1992; Östman & Hansson, 2000) and this in itself I find intriguing. What is even more interesting to me is that the content of mental health

literature concerning the family experience of mental illness which I read in the late 1970's is disturbingly similar to that I am currently reading.

In much of the literature the family experience of mental illness is documented in terms of 'burden' (Kreisman & Joy, 1974; Thompson & Doll, 1982; Francell, Conn, & Gray, 1988). Marsh (1998) categorizes family burden into that which is subjective, "personal suffering experienced by family members in response to their relative's illness", and objective, which is "the practical problems and hardships associated with the illness" (p.54). Other researchers speak to 'stress' or 'psychological distress' as descriptors of the family experience of mental illness (Oldridge & Huges, 1992; Marsh, Appleby, Dickens, Owens & Young, 1993; Saunders, 1999). The terms are used interchangeably and in general make reference to the intense experience of a range of emotions including shock, grief, guilt, shame, and despair, or sorrow. Their emotional response can be compounded by encounters with stigmatization and social isolation, by extreme feelings of anxiety and depression and/or by a generalized decrease in their family's ability to function.

Hatfield and Lefley (2005), well known historical icons for their commitment and persistent work with the families of people with mental illness, demonstrated that in order to cope most effectively and thus maintain their own health, family members require a comprehensive spectrum of treatment and support interventions. But despite the evidence of family burden in research literature and the recommendation that all families coping with mental illness receive support and psychosocial interventions to assist them in coping, fewer than half of American families affected actually received service (Lehman & Steinwachs, 1998). The reason for this appears to be unclear. In Canada, as well as

internationally, there is little research which explores why families coping with mental illness do not receive care (Rose, Mallinson & Walton-Moss, 2004). One may hypothesize that the continued suffering of the families of people with mental illness is directly related to the lack of treatment and support services available for families themselves but is it really that simple? I am not sure! What I do know is that quietly within the confines of their own being they hold the grief of their experience.

My Personal Experience

When one realizes that one in four Canadians experience a mental disorder, it becomes clear that most individuals in our society will interface with a person suffering a mental illness at some point in their life time. This writer is no exception; I was very much aware of a small group of adolescents in the small community where I grew up who struggled with mental illness. My ability to be compassionate towards these individuals was a direct response to the teaching and guidance provided by my parents. They were amazingly accepting and non-judgmental and provided support to families struggling with mental illness. It wasn't until one of my younger sisters developed a mental illness that I began to appreciate the larger context of my parents' perspective. The skeleton was out of the cupboard; our extended family had a history of mental illness.

When my sister first began exhibiting signs of mental illness, I had already left home, completed my nursing education and was nursing in community mental health. Despite our family's understanding of mental illness, grasping the reality so upfront and close felt like I had been slapped in the face. The shock was immobilizing and the anguish unspeakable. The stigma and blame was horrendously pervasive and our family

desperately tried to maintain our honor and some semblance of order in our now chaotic life. We were all affected by the face of mental illness; I think a little piece of each of us died during those first few years.

The condition with which my sister suffers has no cure. The best I hope for is management of the symptoms of her illness. So the effect on our family continues. When she is stable, I (and the rest of my family) enter a period of blissful respite in which I try to dissociate from the pain. But just under the surface I am watching and waiting for the appearance of that tiny crack that warns of the turmoil ahead. There really is very little rest or peace on the horizon and when she falls through the ice one more time the grief cuts my heart again and again and again. It never ends. We have been dancing this tune with my sister for 20 years and interestingly my family has never spoken with a health care professional about her condition. Just recently during my sister's last episode, my 78 year old mother commented, "I've turned the picture of her on my dresser around...she now faces the wall...it won't end until the end." My suffering and that of my family has been and continues to be excruciating.

My Professional Experience

The different faces of mental illness I encountered as an adolescent intrigued me and inspired a passion which called me to mental health nursing. I have never regretted my decision to work with people with mental illness and their families; I have learned so much from them and thus perceive my nursing practice as a distinct privilege (for which I am very grateful). The development of my nursing practice has been evolutionary and, in the last ten years particularly, I have come to appreciate how my clients have contributed

to the co-creation of my development of a caring nursing practice. They taught me to listen: to listen closely, intently, and without judgment.

Heidegger, in his writing on language, makes this profound statement: "We are always speaking...even when we do not utter a single word aloud...even when we are not particularly listening" (Heidegger, 1971, p.187). He goes on to say that to "place language means to bring to its place of being not language but ourselves" (p.188). In my family work, I generally began my first session with a family member, with a request to hear their story, I was always moved by their response. I would give them the time they needed and sometimes it took as many as three sessions. I spoke very little and worked hard at giving them my undivided attention. The few questions I did ask generally clarified their perception of an aspect of their experience. What always amazed me was that many of them would indicate how helpful these first sessions had been. All I did was listen and gaze under the surface in an effort to understand. In so doing, in a very small way, I shared in their experience and it seemed like such a privilege. I often sensed that the families responded more to my willingness to 'be with them' than to any information or strategy I could provide them. There was a connectedness that was very different from that which I experienced working with people who had a mental illness. Family members often appeared desperate to understand their own experience differently and somehow by articulating their story they constructed new meaning.

Heidegger (1971) also contends that language bids things to come nearer. I believe it was the bidding that I heard in the conversations with family members of people with mental illness, that challenged me to understand their experience more deeply. I often had a sense that we were moving toward something, only to move away

from it again. There was more there and we both knew it. It was compelling; I knew I had to understand their experience differently.

I began simply to examine the word 'burden' because it is the word commonly used in the literature to describe the family experience of mental illness. But burden conjures up in my mind a large awkward package carried on one's back that is so heavy that it makes one stoop over. It is not part of the person carrying it; on the contrary it is somehow strapped onto their back. Implicit in the picture is a sense that if one was really motivated, if they tried hard enough, they could make a choice to offload the package and rid themselves of the burden. From my perspective this does not capture the experience of the families of people with mental illness. Their suffering is catastrophic and permeates every part of their existence; it is their life. There is no option to offload it, even temporarily.

When I realized this I began to understand a little more clearly why telling their story was so important. I acknowledge I know very little about their situatedness and somehow the literature also has not captured their reality very accurately. Through this research my hope was to provide the families with room to share their experiences and then to explore the way we talk and write about their experience in an effort to bring closer together what we understand and what they actually experience (their lived experience). I know that there will never be one truth about their experience but I believe there is room for deeper understanding.

Research Question

There is no doubt in my mind that the suffering of families of people with mental illness continues and is profound; it is clear in the literature (Hatfield 1997; Marsh, 1998,;

Milliken & Rodney, 2003; O'Connell, 2005; Saunders, 2003) and is affirmed by my personal and professional experience. I have contemplated why this may be so and have been compelled by the question, what is the family experience of suffering about? Do we really understand suffering, as it is experienced by families with a mentally ill relative? Have we articulated our understanding? Why is it that the literature does not speak to the 'suffering' of the family members with an ill relative but rather has chosen the word "burden" as a descriptor? Is it possible that implicit in this word choice is the ideology of self efficacy and possible blame? Is there an underlying presumption that one could offload the burden if they chose to? Are we reluctant to use the word suffering because we don't clearly understand their experience? Is this perhaps why nursing literature has not extensively explored and examined the concept of suffering of families of people with mental illness (Dewar & Morse, 1995; Morse 2000, 2001)? Some claim we no longer blame the family for the mental illness of their relative, but I'm not sure about this assertion (Marsh, 1998; Hatfield, 1997). I ask myself, who has made this claim and on what basis? I would like to understand why the suffering of the families of people with mental illnesses continues despite the changes in the treatment approaches of their ill relative. Perhaps we are not asking the right questions to the right people? Perhaps it has not been safe for family members to answer honestly? Perhaps we haven't been willing or able to hear or understand the answers given. I would be honored to be given the opportunity to ask the question, "What is the experience of suffering for families of people with mental illness?"

Significance of the Research

While working with the families of people with mental illness in a professional setting, I developed an awareness which was in some ways intriguing but also troubling. It was directly related to my bearing witness to the family experience of mental illness and my ability to integrate the experience and my knowledge into a caring and therapeutic relationship with them. This awareness had a mysterious quality to it and seemed to emerge from a deep emotional place and I came to recognize it as a powerful sense of compassion. Nouwen (1982), a renowned spiritual teacher and counsellor, states that compassion is a natural human virtue which “constitutes our core of human motivation” and that through compassion our “humanity moves into fullness” (Nouwen, McNeill, & Morrison, p.5). What is significant in this inquiry lies in our capacity as civilized human beings to show compassion toward each other, particularly in the face of suffering. In order to be compassionate with the family members of people with mental illness we must understand their experience of suffering: the plight of their suffering, the implications of their suffering, their emotional and behavioral responses over the course of their suffering and the response of others to their suffering (Morse, 2001). Only in the fullness of our understanding of their experience will we begin to know something of how to be compassionate, to fully immerse ourselves in the condition of being human.

Over the past two decades, there have been shifts in how family members are treated by the professionals caring for their ill loved one. It has been demonstrated that that family attitudes can influence the course of mental illness and that involved, well informed families can be an asset to the client (Cuipers, 1999). Marsh (1998) contends that positive changes in attitudes toward family members by health care practitioners are

evident in their moving away from blame to a willingness to accept family members as equitable partners in the treatment team of the client. Treatment approaches of mental illness have also changed considerably; early intervention initiatives, new pharmaceuticals with less debilitating side effects, and commitment to community rather than institutionally based care have significantly affected the illness trajectory. But my interpretation of current literature is that it continues to reflect the suffering of the families of people with mental illness. It seems that although our culture's approach to health and healing has resulted in advancing the scientific model of research and practice and thus increased our ability to diagnose and treat medical symptoms, it has been less effective in its ability to relieve human suffering (Simmington, 2004).

The relevance of this inquiry was not to lay blame or locate a need for correction; it was rather a desire to understand more fully the essence of the suffering of the families of people with mental illness. Heidegger (1971, p.59) speaks about truth as an "Open" and the need to create space in which the "not-yet-uncovered and the un-uncovered" (or concealed) shows itself. This research provided an opportunity to create or bring forth the possibilities that pertain to the suffering of the families of people with mental illness which inform the experience itself and thus add to the understanding of the experience shared. As in the Greek sense of thesis, this inquiry is "setting up in the unconcealed" and intends to bring to word and appearance something that is (Heidegger, 1971, p.59). In this inquiry I 'set myself up' in the family experience of mental illness to articulate or give language to, the suffering they experience.

Understanding the family experience of mental illness is foundational to working with people with mental illness in a professional capacity. For nurses, particularly those

who work in acute or community mental health settings who frequently have access to the families of people with mental illness, the understandings generated through this research may be useful in their work. The governing body of nurses in British Columbia (the College of Registered Nurses of British Columbia [CRNBC]) is clearly committed to a high standard of nursing practice when it unequivocally endorses the principles of universality, comprehensiveness, accessibility, portability and public administration as stated in the Canada Health Act (1984). Moreover, the CRNBC has also stated their full support of the five principles of primary health care (accessibility, public participation, health promotion, appropriate technology and intersectoral cooperation) as foundational to a sustainable health care system in British Columbia. They challenge all nurses to provide health promotion, disease and injury prevention, and curative, rehabilitative and supportive care to as many people as possible regardless of their health condition. This demands that nurses (as well as other professionals) engage in a therapeutic relationship based on participation from and collaboration with clients and their families in an effort to understand their experience and promote an optimum level of functioning.

The Canadian Nurse's Association (CNA) directs nursing practice even more specifically when it identifies nurses and particularly Advanced Practice Nurses (APN) as "change agents" and in this role the nurse would "demonstrate an understanding of ... issues that influence decision-making and develop strategies to influence health and well being and health policies" (CNA, 2002, p. 9). This challenges nurses to not only provide the best nursing care possible but to take responsibility for education and communication with health care administrators and political leaders. It places the responsibility of clearly articulating the experiences of our clients and their resulting health care needs well within

the scope of nursing (Hamric, Spross & Hanson, 1996). Furthermore, this inquiry may contribute to the profession of nursing by strengthening the use of conversation or dialogue as an approach to nursing research.

Conceptualizing the Landscape

In order to understand the context of this inquiry one must introduce the concepts of the landscape, the beings which have been bidden to the Open. The beings in this inquiry include mental illness, family and suffering.

Mental Illness

According to Health Canada (2006), when people have the capacity to feel, think and act in ways that enhance their ability to enjoy life and deal with the challenges they face, they are generally considered mentally healthy. Mental health is a positive sense of emotional and spiritual well-being that respects the importance of culture, equity, social justice and interconnections and personal dignity. Alternatively, when one experiences alterations in thought, mood and/or behavior which are associated with significant distress or persistent pain that consequently seriously impairs a person's day-to-day functioning, they may be seen to suffer a mental illness. Mental illness can be characterized by mild to severe symptoms depending on the type of mental illness, the family and the socio-economic environment. Mental illness can take many forms including mood disorders, schizophrenia, anxiety disorder, personality disorder, eating disorder, as well as addictions, such as substance dependence and gambling. Although this definition serves many functional purposes in the diagnosis and treatment of mental illnesses it does however, from my perspective, seem limiting in its ability to capture the concept of mental illness more comprehensively.

The term mental illness implies a distinction between mental illness and physical illness which is steeped in mind/body dualism. Over the past thirty years, postmodernists have challenged this thinking and authors such as Frank (1995) capture a shift in illness

representation when he states that “modernists would locate the truth about illness in the doctor’s story, whereas the postmodernist truth about illness is increasingly heard from the client’s story” (Frank, p.6). Rather than the dualistic, mechanistic and reductionist, biomedical model that focuses on the prevention of disease, postmodernists view human illness as “unique experience of meaning making and embodied cultural being” (Morris, 2000, p.8). This is much more in keeping with my perception of mental illness. The medical model objectifies the body and this promotes the sense that an experience of mental illness is something separate from one’s self, a condition which must be alleviated or removed for mental health to return. In my nursing practice I observed people living with mental illness and their families who had the tremendous capacity to appreciate that they existed as part of their illness experience; they lived through the experience. That which was happening in their embodied experience they accepted as their life and they were able to somehow find renewed joy in their lives. This incredible transformation affirmed to me that the concept of mental illness or mental health cannot be defined on a continuum; its meaning is not simple or one dimensional. It is much more about a person’s subjective experience of their world and in keeping with the theoretical foundations of hermeneutical inquiry. Mental illness is multi-dimensional and multi-layered and it’s essence cannot be captured in a single definition.

In this research, the term “mental illness” will then be very broad. It takes in diagnosed mental illnesses (e.g. Depression, Anxiety, Delirium, Personality Disorders, Post-traumatic Stress Disorder, Schizophrenia, Bi-polar Disorder etc.) in either the prodromal, acute or chronic phase of the illness. It includes mental illnesses that are successfully or unsuccessfully being treated and illness that is not being treated at all. It

incorporates mental illnesses that are acute or short lived but also those that go on for a life time. It includes those that are episodic in nature as well as those complicated by substance use and/or abuse. In this inquiry, my intention was to be inclusive of family members from a broad range of mental illnesses

Family

Perhaps one of the greatest anthropological and sociological shifts of the past few decades is that of the changes in what is perceived as family. Historically family has been defined according to structure and function, but particularly in the last ten to fifteen years these definitions have been challenged to take up existing changes in family form (Doane & Varcoe, 2005). In more recent nursing literature, the constitution of contemporary families is captured in definitions such as the following one provided by Hansen (2001), which states a family is “two or more individuals who depend on one another for emotional, physical and economic support” (p.6). It is now generally accepted that members of a family are self-defined and that “the family is who they say they are” (Wright & Leahey, 1994, p.40). A further shift in the definition of family is occurring within nursing. Rather than assessing families from a specific theoretical lens, such as a systems or developmental perspective, there has been an “opening-up” to see and understand families relationally (Hartrick, 2002). Doane and Varcoe (2005) assert that in relational family nursing we are reminded that there is no truth of family but many possible interpretations, thus the aim is to gain an understanding of the meaning of family for client(s) one is working with. To give an example of this, I have counselled a group of three neighbors of a young mom with schizophrenia. This young woman lived in the basement suite of a home in the area where the group of three lived and had a child who

played with their children. The three neighbors were the young woman's primary support and they became her surrogate 'family'; they supported her and her child socially, financially, and emotionally. Whether we are working with a traditional family or a person who at a specific time in their life has few ties with others, the goal remains the same; nurses need to understand less regarding the facts about their client's family, and more about what meaning family has for them. This understanding will help create the context in which family members experience suffering.

From a hermeneutic phenomenological perspective, assumptions regarding family accept that family experiences are situated in and constituted by the world and are thus influenced and shaped by the world. It follows then that experiences of family are unique but also have shared meanings. It also assumes no objective truth about family experience and accepts that knowledge is only relevant in the context of family understanding (Doane & Varcoe, 2005). For example, all families who have a member suffering schizophrenia do not have the identical experience. What is significant for one family may be very different from that of another family, depending on how they are situated and constituted. Furthermore, understanding of the general disease trajectory of schizophrenia only becomes relevant within the context of family knowledge and experience. From this perspective, families are as diverse as they are in number, and the experience of having a relative with mental illness is unique but also has shared meaning. This inquiry explored the experience of suffering as lived by families of people with mental illness; it endeavored to assist me in grasping a deeper meaning of suffering for these families. Although I had many questions (such as how has exposure to terms such as patient confidentiality, compliance, and concepts such as personal autonomy, the right

to live at risk and family as primary care-giver affected them? How does their family understand illness and health? How has their experience affected the beliefs and values of their family?), I did not present these questions directly to family members, but rather, through a process of reflection and interpretation of their stories, and their narratives, I hope to broaden the horizon of understanding of the experience of suffering for this population.

Suffering

The experience of human suffering has occurred in every age of human existence. The concept of suffering continues to be grappled with by theorists, philosophers, and theologians. In health care, questions such as the following persist in the minds of health care providers and their clients: What is suffering? What is the meaning of suffering? Why does some suffering leave us so wounded and other suffering enrich our lives? Does our culture deny suffering? Bearing witness of suffering is pervasive for health care providers and as such the discourse of how it should be defined is alive and well. Morse (2000) contends that “professions, the so-called caring professions, have been designated as responsible for responding to the cues of suffering” and furthermore she identifies an urgent need to explore the nature of suffering from a variety of research perspectives (p.1).

Much of the contemporary discussion on suffering in nursing literature begins with Cassell’s (1982) description of suffering as “severe distress associated with events that threaten the intactness of the person” (p.640). He expounds on this description stating that suffering affects the entire person and is correlated to the meaning the person attaches to pain or suffering (Cassell, 1991).

This description resonates with me as it moves away from the dualistic thinking that suffering occurs in the mind and pain occurs in our body. Cassell very clearly locates suffering in the person. It may be a physical experience, however when considered more broadly, it is “a complex dynamic experience that overarches the individual’s life experiences and includes physical, social, spiritual and emotional domains” (Sacks & Nelson, 2007, p 675). By locating suffering in the person, it is an individual matter, and Cassell invites us to consider one’s situatedness within the world. Our reality of suffering then is constituted by our interaction with the world and “the world is not what I think but what I live through” (Merleau-Ponty, 1962, p.xvii). This inquiry seeks to explore what family members of people with mental illness live through. Its intention is to gain a deeper and broader understanding of what the experience of suffering is about.

Approach to the Inquiry

To know a situation, one needs to sense what lurks in it.

James Hillman

Philosophical Tenets

Posing a question allows one to wonder about something. It encourages thought and reflection through which the mystery of a phenomenon is brought more fully into our presence (van Manen, 2003). Gadamer emphasizes that the process of reflection and understanding are inseparable (Johnson, 2000). When I reflect for example, on what the experience of suffering of families of people with mental illness might be, I position myself to better understand, and when I understand more fully, my reflections bid me to come nearer to deeper or more challenging questions (Heidegger, 1971). At the heart of this hermeneutic phenomenological inquiry is a commitment to understand something of the way we experience the world, the world of suffering distinct to the family members of people with a mental illness. My concern is to discover aspects or qualities that make the suffering of the families what it is and without which suffering of the families could not be what it is (van Manen, 2003).

The philosophical underpinnings of this type of inquiry lie in existentialism and thus focus on lived experience and a belief that human experiences are constructed from multiple realities. It concentrates not on categorizing or explaining, common approaches of natural science inquiries, but on a process of creative description and interpretation of human experience. I am less concerned about defining burden, or categorizing the stages of grief in the experience of mental illness. What I am passionate about is hearing their story or their experience of grief or burden. From their stories I developed an

interpretation which is to be captured in this text. Through this process of interpretation, in which the role of language is pivotal, and there is an acknowledged interplay of part and whole, there evolves the creation of what hermeneutic philosophers consider to be human understanding (Smith, 1994). In this hermeneutical inquiry there was then no emphasis placed on determining a finite truth about the suffering of family members of people with mental illness, but rather an exploration of the nature and essence of this suffering which would provide a richer and deeper understanding of this phenomena. There is also an assumption that the conversation about suffering is unending.

Researcher as Instrument

In this hermeneutical inquiry, the researcher is the instrument for data collection and thus the credibility of the method is largely dependent on the skill, competence and integrity of the researcher (Patton, 2002). The researcher must adopt an attitude of openness in which one can wonder and be challenged by the conversation, in which the taken for granted can be questioned and there is commitment to engaging possibilities as they arise (McDonald, 2005). As such the researcher must have good interviewing skills, be an effective communicator and have the ability to exercise interpretive and empathic listening (Kvale, 1996).

As the researcher compelled to initiate this inquiry, I must acknowledge the tremendous feeling of honor I feel when I contemplate the journey I embarked upon. I am a Registered Nurse (RN) who has counselled people with mental illness and their families for over 25 years and I have a deep commitment to this population. In my nursing practice I have had the opportunity to work very independently and thus was able to develop a philosophy of care that was consistent with my values and beliefs. To that end I

have been committed to working collaboratively with my clients from a health promotion perspective. I am acutely sensitive to hierarchies that tend to reinforce oppressive approaches of power and concentrate on openness and mutual self-giving as experienced in empowerment. I am presently teaching at the local college and over the past four years have taught a variety of interpersonal relationship courses in the School of Nursing. I feel my experience in private nursing practice, in teaching student nurses, as well as my personal family experience with mental illness in many ways prepared me to be able to share in the stories of the participants.

Participant Group (Sample)

Interpretative inquiry places emphasis on in-depth understanding rather than generalizability and thus the sample size is proportionately smaller (Polit & Beck, 2004). Through third party recruitment by local mental health agencies (see Appendix 1), I engaged seven family members for an in-depth interview. All participants who volunteered were accepted for the study and all were adults. Participants were given my contact information and they initiated the first contact with me by email (password protected) or telephone. In our first communication, I briefly reviewed the intent and approach of the research and answered any questions they might have had. This was followed by collaboratively securing a date the interview could take place.

The question of dual relationship was important at this stage in the study. Because I have been in private practice for many years, and because many of the families I have worked with are aware of my intent to do this research there was a possibility that families I have worked with may volunteer as subjects for this inquiry. In a therapeutic relationship, dual relationship occurs when two roles are simultaneously engaged, in this

case the role of a counsellor and that of a researcher (Blackwell, Strohmer, Belcas, & Burton, 2002). I asked myself the question; to what extent might the dual roles of counsellor and researcher potentially lead to divided loyalties? I believe it important to note that I have not been in a counselling role with families of people with mental illness since the onset of my graduate studies.

On closer examination, an issue that arose is one of an ethical nature, namely whether previous knowledge about a family's experience, gained in a therapeutic relationship, could negatively influence the findings of the inquiry. I recognized my concern as an issue of bias and validity in research studies and it encouraged me to deepen my understanding of how these concepts are approached in hermeneutic inquiry. I found myself returning to the literature and seeking consultation from researchers experienced in Hermeneutic inquiry. After reflecting, I realized that in many studies, particularly those approached quantitatively, the focus is on empirical generalizations and concern of internal validity is often overcome, in part, by random sampling (Polit & Beck 2004), but in hermeneutic inquiry it is quite the opposite. This study was strengthened by dialoguing with families that I may have counselled in the past. Patton (2002) maintains that conversing with information-rich families will often yield insight and in-depth understanding (Patton). For this reason, understanding some of how a family is situated (by way of a previous therapeutic relationship), may be an asset to both the family member and to the inquiry at hand.

Furthermore, the family members I have worked with in the past have contributed to the evolution of this inquiry, through conversations with them I was 'struck' by the suffering I observed and was 'taken' by how the suffering was interpreted as burden. It

opened up something which they are very much a part in and to potentially exclude them from the conversation would be uncaring and disrespectful.

To this end, of the seven participants in the study, one was an individual I had previously counselled. I will add however, that while actively engaged in this study, I did have several opportunities to converse with family members with whom I have been in a professional relationship or whom I knew personally and had knowledge of their family experience of mental illness. Consistent with a hermeneutical research approach, these conversations contributed to the richness of the understanding gained (Fleming, Gaidys & Rob, 2003).

Participants

To assist in the analysis, interpretation and writing of the findings of this study I initially thought it important to identify the individual participants with a pseudonym. But as I looked, listened, read and wrote I found myself becoming bound. I realized I was becoming preoccupied with who said what rather than what was said. The following reflection captured my thoughts.

I'm feeling distant from the words and preoccupied with the names and it's irritatingly confining. Although I am genuinely committed to accurately tracking who contributed the quotes I use in the discussion of the findings, it's compartmentalizing the content and detracting my ability to 'be with it' as a whole. It's interfering with the hermeneutic circle which is so essential to the interpretive process. The circle pictures the dialogical movement among the part and the whole. If I am going to expand and deepen my understanding I need to freely be able to move back and forth between the part and the whole while free to return to my beginnings. It's a fluid process which extends the circle as I integrate new understanding (personal journal).

In order to maximize both my ability (and that of my readers), to absorb themselves freely in the text I will give a very brief and general description of the participants and

the nature of their relationship with their ill relative. I will identify their words collectively by placing them within quotation marks.

In this study, I had the distinct privilege of having conversations with two mothers, each of whom had an ill son, a sister with an ill brother, a step mother with an ill stepson, a mother with an ill daughter and son, and two fathers with an ill son (one of whom also had an ill brother). The ill relatives suffered from a range of mental disorders including: psychosis, schizophrenia, obsessive-compulsive and schizoid personality disorder, depression and suicide, and concurrent disorder, bipolar disorder, paranoia and drug addiction.

Interviews

In planning for the data to be collected through in-depth interviews of family members (Patton, 2002), I made every attempt to create a safe and positive atmosphere in which the family members would feel comfortable sharing their personal life stories (anecdotes, stories, experiences, incidents) freely. Participants were given choice regarding the location of the interview; two of them chose to meet in their homes, one chose to meet in her office, one chose my home and three chose my office. I was extremely cognizant of the privilege of hearing the family member's lived experience and empathically attended to the spoken and unspoken meaning communicated (Kvale, 1996). By entering the life world of the family member through conversation (see appendix 4 for interview questions), a process of understanding the other began evolving. This process did not occur as a result of the researcher attempting to see through the eyes of the family member their experience of mental illness, on the contrary it is about the researcher and family member working together to reach a shared understanding

(Fleming et al, 2003). I engaged in close observation and ensured that anecdotes were “not merely sand in the hand that disperses upon gathering it” but rather had a point significant to the study (van Manen, 2003, p.68). Close observation is a method of conscious reflection I engaged in while participating and observing in the conversation. I took written notes of observations and emphasis reflected by family members and each participant consented to having their stories audio taped. The audio tapes were transcribed verbatim by a professional transcriber (who signed a confidentiality agreement – see Appendix 3). The conversations were well spaced, never occurring within two weeks of each other. This provided ample opportunity to ‘sit with’ or begin to analyze the data collected: to listen once again to the taped conversation while reading the transcribed copy, to revisit the literature applicable to the specific data collected and to immerse myself into the process of interpretation. Prior to each conversation with another participant, I prepared myself by listening to pieces of previous conversations, reviewed my reflections and notes. New understanding gained was then taken into subsequent conversations. This is in keeping with what Gadamer (as cited in Fleming et al., 2003) has termed the Hermeneutical Circle and will be described in the interpretation section of this document.

Conversations with various family members continued until they had no more to tell. Conversations were concluded when the content became repetitive and I became confident that the phenomenon in question has been adequately captured (Gillis & Jackson, 2002; Polit & Beck, 2004).

Interpretation

As stated previously, in hermeneutical inquiry the collection of data and analysis occurs simultaneously and as such the research process also simultaneously becomes the interpretive and writing process (van Manen, 2003). My goal was not to provide for the reader short excerpts or quotes from family members that would speak for themselves, rather my hope was to explicate themes that are the threads to be woven into descriptive paragraphs which provide a deeper understanding of the phenomena in question. I immersed myself in the text (audio taped and written words of participants, anecdotal comments and observations made by the researcher in the form of notes) and dwelt on it by reading it, listening to it and discussing it over and over again. I worked back and forth between parts of the descriptions or stories and the larger context of complete stories to make sense of words, ideas and emotions (Patton, 2002). This movement, back and forth, from the whole to the part and back to the whole again is what Gadamer calls the hermeneutic circle (Johnson, 2000). Every comment or sentence made by a family member was considered for its potential to further understand the family member's experience of having a relative with mental illness. The meaning exposed challenged my preunderstandings and moved me to a deeper and broader understanding of their experience. The process of engaging in the conversational interview and analyzing the text was not rushed but given time to incubate and allow new insights to emerge which disclosed meanings of the family members' lived experience (Speziale & Carpenter, 2003). The new meaning or understanding evolved through analysis of the text, at any given point, was taken to subsequent conversations and thus new understanding was constantly evolving (Fleming et al. 2002). My intent was to make the "object (suffering)

and all its possibilities fluid” (Gadamer, 1989, p.579), and this process could really go on indefinitely. Each read or conversation (the part) challenged my understanding (of the whole). Immersing myself into this process seemed easier than trying to extract myself out of it and speak to my understanding at the given moment I had decided was timely for this inquiry. When the learning is evolving and rich it is difficult to draw it to a close. The conversational interviews in this project took place over a period of four months.

As in all research projects, it is essential for the researcher to ensure the credibility of the research process. This has been a challenging and evolving process for qualitative researchers. Lincoln and Guba (1985) have determined “trustworthiness” as an evaluative criteria while others such as Fossey, Harvey, McDermott and Davidson (2002) consider “congruence or fit” (between the research question and research process) and “what was learned” is essential evaluative criterion. While the dialogue continues and new criteria continue to be developed, Morse (2003) cautions qualitative researchers of “the trend to use standards to evaluate qualitative studies that focus on the techniques of doing the study rather than on the findings or contributions”(p.558). Koch and Harrington, (1998) have suggested that in Gadamerian hermeneutical studies, credibility can be established through “detailed and contextual writing and a reflexive account of the actual research process” (p.886). Sandelowski and Barroso (2002) have recommended qualitative researchers use the word “appraisal” to deal with the issue of rigour because it more explicitly captures the ideas of understanding and value or appreciation.

Thus, to return to this inquiry, I believe the credibility of the study has been established as I have been open and transparent throughout the research process: I have been explicit about the development of my research question, open about my history (my

context), honest about my preunderstanding or prejudice, and to the best of my knowledge, have been unequivocally committed to a critical and reflexive stance in conversation and analysis.

Ethical Considerations

Ethical considerations are paramount in all research studies and because of the developmental nature of this and other qualitative inquiries traditional procedures to ensure ethical conduct are difficult to apply (James & Platzer, 1999). "Yet, the requirement to behave ethically is just as strong in qualitative inquiry as in other types of research on humans -- maybe even stronger" (Rubin & Rubin cited in Patton, 2002, p.411). Of particular concern in this study are issues of confidentiality, consent, and the researcher-participant relationship.

Prior to beginning the inquiry, a 'Joint University of Victoria and the Vancouver Island Health Authority Ethics Application for Human Participant Research' was submitted and approved by the Research Review and Ethical Approval Committee. All administrative personnel involved in the transcribing of the interviews completed a confidentiality agreement, which safeguarded the privacy of all study participants and protected the confidentiality of their personal information.

Because of the evolving nature of this inquiry, the consent signed by family members was free, informed and ongoing (Polit & Beck, 2004). I clearly indicated the intent of the study and any real or potential benefits or risks to family members. I made every attempt to develop a trusting relationship with family members by intentionally being transparent around the purpose and the process of the study, by being respectful of their persons, and by being very mindful of their responses. Clarification on the research approach was necessary in most cases and participants were also keenly interested in what led me to undertake this study. When it became apparent that the participant clearly comprehended the purpose of the inquiry and the nature of his or her involvement in it,

informed consent was attained and the participants signed the consent form (see Appendix 2). Commitment to ongoing consent was reflected in my seeking permission to proceed several times throughout the interview process particularly following difficult or unexpected responses.

Potential benefits to family members may include experiencing a sense of relief to be sharing their lived experience. Alternatively, family members may have a negative experience when the question I asked may trigger a stressful emotional response to past experiences. It is at this point that I gave careful consideration to the boundaries of my role as a researcher (James & Platzer, 1999). With all family members but particularly with the individual I had previously counselled, I committed to setting aside time which would give them the opportunity to voice specific questions, (of a counseling nature) related to their ill family member. This time was utilized by five of the six participants involved in the study and this portion of our conversation was not included on the audiotape. In the event that family members became distressed, I was prepared to debrief with the person, call someone of their choosing to support them or refer them to the services of a counsellor to assist in dealing with the emotional response they were experiencing. I am grateful that the experience of the family members did not appear to cause undue distress, this notwithstanding the significant emotional responses experienced by the family members while engaged in the conversation.

Acknowledgement of the emotion expressed and a simple pause imparting assurance of the time and space they needed to gather their strength appeared to provide the support required. Family members were made aware that their continued participation in the

study was completely in their control and that they could choose to bring the interview to a close at any time without consequence. All participants completed their interviews.

A final ethical consideration revolves around my commitment as the researcher to be transparent in showing how I arrived at the interpretation I have and what decisions I made to come to new and deeper understanding. As Smith (1994) says, because this inquiry occurs in the life-world, it requires a giving of one's-self over and a staying with each other in conversation. In this way the truth that is realized in conversation, is owned by neither but shared by all. I have heeded Smith's challenge that a hermeneutical researcher needs to be prepared for the deepening of one's self-understanding and as such have been committed to reflexive/ reflective journaling of my trek through this process. I have documented my thoughts, interpretations and decisions in an effort to leave a transparent trail that could be followed by others. What follows is a short excerpt from my reflections:

The stories are heart wrenching and I felt guilty encouraging them to feel their pain one more time. They were willing to share with me on the off chance it could help others going through this. I found myself hearing my skeptical voice asking will this really make a difference...will it only just fall on the deaf ears of politicians, health care administrators and policy makers. In a small way I found myself thankful that I wasn't their counselor, this time I wasn't actively clinging to some sort of professional objectivity that would permit me to encourage them to move past their challenges. No, this time I am the researcher doing a qualitative study that compels me to surrender myself to them, to go with them into their story, to share in their experience ever so briefly. This was much different than "bearing witness" the suffering families experience; it was willfully engaging, becoming part of their life for just a few hours. It was in some ways like walking into an unrelenting wind, purposefully moving toward the other despite the resistance and embodied struggle to turn one's back, cover ones face, curl up down low. It was about acknowledging how the wind (words/truth) stole my breath, stung the skin on my face, brought tears to my eyes and at times knocked me flat off my feet. Can I ride out the wind in anticipation of the calm after the storm? Will I be able to face the new horizon? Will I recognize that which remains (personal journal)?

Expanded Understanding

Family members participating in this study report that the occurrence of mental illness can be sudden or very insidious and generally occurs in late adolescence or early adulthood. This has been substantiated in current and historical literature (Marsh, 1992; Saunders, 2003). Family members have also shared that, for many, the prodromal signs of the illness were evident long before a diagnosis was made and treatment implemented. Throughout this inquiry, it became clear that families spoke to their experience by identifying a number of phases. These phases included the time before the onset of their relative's illness, the time when they were beginning to recognize the face of the illness and sought out initial support, the phase of treatment and management of the acute symptoms of their relative's illness, and finally the long term phase – the ongoing care and support of their ill relative. For the purpose of clarity, the findings of this study have been organized into three sections: 1) recognizing mental illness, 2) the day-to-day management of the symptoms, and 3) the long-term care and support. Included within each section are the descriptors used by the family members applicable to the specific phase of the illness trajectory or path.

“When tragedy makes its unwelcome appearance and we are deaf to everything but the shriek of our own agony, when courage flies out the window and the world seems to be a hostile, menacing place, it is the hour of our own Gethsemane. No word, however sincere, offers any comfort or consolation. The night is bad. Our minds are numb, our hearts vacant, our nerves shattered. How will we make it through the night? The God of our lonely journey is silent.” Brennan Manning

*i) Recognizing Mental Illness**Lost*

“Our illnesses started at the same time, mine and my son’s; he got schizophrenia and I got fibromyalgia.” So begins the story of one family member’s account of the experience of mental illness in their family. Her voice is barely a whisper. There are long pauses: unspeakable anguish. She swallows, wipes away the tears, apologizes and slowly articulates a few words at a time, he’s really a good boy...artistic...gentle.” Another family member described the insidious onset of mental illness this way, “over the course of the next couple of years, um, I had some difficulty...I would say to my husband, I can’t find him... I have visited with him, but I just can’t find him.” “He’s lost.”

Unsuspecting

Family members talk about intuitively knowing or sensing something was wrong with their ill relative, but putting it out of their mind, rationalizing that the behavior was a result of something different, a challenging developmental phase (the incorrigible teenager), the recreational use of substance or a reaction to a difficult life experience. Many shared they had no experience with the behavior they were confronted with and when “it didn’t go away I called my friend” rather than a health care professional. The process of coming to the realization that their ill relative needed medical intervention was long and family members shared that they wished they had been more knowledgeable and intervened more quickly.

Conflicted

One family member stated that, although she was concerned about her daughter’s condition, “ I didn’t do anything about it because I thought it was (her) life and she could

do it.” The onset of mental illness often occurs in late adolescence or early adulthood, a time in life when many individuals strive for independence and autonomy from the family unit. Furthermore, youth and young adults in our culture are free to access medical services on their own accord as soon as they demonstrate they understand the implications of their medical decision. This creates a conundrum for family members coping with a relative exhibiting signs of mental illness; how does one encourage their ill relative to get the medical help they need without undermining their ill relative’s right to self-determination? Despite the ardent claims of ill relatives that the encouragement and support of well meaning family members was personal interference, many family members gave account of how they urgently persevered in their attempt to get their ill relative medical treatment. The tension it created paled in comparison to the symptoms that were attacking their ill relative’s body. Their diligent persistence was embedded in the assumption that once their ill relative received medical treatment “things would get better” again. But would they?

Disconnected

The devastation of “losing” a relative to mental illness was a consistent notion in the stories of families dealing with mental illness. Family members shared that they desperately ached for connection with their ill relative but that mental illness robbed them of this ability. The inability to be in relationship created an insurmountable abyss, a separation so deep it is like a “death.” The embodied presence remaining is that of “a child you haven’t given birth to,” a stranger, or an imposter who exists within your experience but whom you don’t know or isn’t who they seem. Their relative’s new presence, however disconnected, deeply impacts those they have been in relationship

with, particularly those within the family unit. One family member stated, “illness began to permeate the family unit” and “everyone takes on their (relative’s) mental illness.” For some family members it took the form of tremendous anxiety, for others, an impending sense of fear or depression and yet for others a physical condition such as hypertension or insomnia.

ii) Day-to-day Management of the Illness

Unbearable

The term family members used to describe their initial experiences with mental health services included “absolutely devastating and horrible.” Family members told of how they encouraged, pushed and cajoled until their ill family member would accept being assessed by a medical profession. With anticipation many described heading to the local emergency department assured that this was the best course of action. What they found though was something they least expected. One family member shared, “it’s a very long process and it was pretty ugly...we were in a horrible little room with no windows just a viewing door and a cot, a cast-iron cot...it was at the back of emergency and the only other person there was someone who was obviously in distress, indigent, and had been brought in by the police. The police weren’t very respectful; it wasn’t a nice environment at all. So (my son) and I sat there for three or four hours waiting, all the time (my son) wanting to go and I’m saying, let’s hang in there.”

Betrayed

The wait was agonizing. Family members shared that they felt ignored by the medical staff and they themselves began questioning whether seeking treatment was indeed the right approach. When their ill relative was finally taken into a room where a

mental health assessment could take place, family members stated that they waited again. Medical professionals appeared not to want any corroborating information from them nor were they aware of the family's need for support. Another family member stated "they (the medical professional) flat out said he was schizophrenic; I had no idea what that meant but I knew that it was a very, very bad thing." Another family member spoke of her son, despite being quiet and subdued, being transferred to an in-patient unit in "awful prison garb under the protection of security guards" rather than accompanied by his family and realized that seeking treatment was not going to be "too gentle." "I wanted him in a caring supportive environment somewhere where he would be looked after and that wasn't it" she said with resignation, "we worked harder to get (their relative) out of hospital than they did to get him in."

Guilt

Family members were quick to point out there is a place for security guards but that their distress revolved around an assumption that all people with mental illness were potentially violent and security guards were needed in all situations. This generalization compromises the individual needs of the person. Family members felt their ill relatives were not seen for whom they were, gentle, kind and cooperative people in need of health care, but rather they were judged and treated as if they were criminals, outcasts, or indigents. A mother shared that she, at a specific point, called the local crisis line to access an emergency response team and while she was on the telephone explaining to the operator that her son did not require police intervention as he was cooperative and not violent, a loud knock on the front door prompted her son to open the door and before she could get off the telephone he was tasered by the two police officers at the door. The

assault to his physical body paled in comparison to the assault on his core sense of self (or spirit). One family member shared that her son “never really got away from ‘policing’ rather than support and help.” The dissonance, guilt and remorse family members experience around encouraging their ill relative to access treatment is profound. It is also not limited to the initial contact phase of accessing service. Some family members were so traumatized by their experience of having their loved one admitted involuntarily, they vowed they would never be part of that process again. This position in itself exacerbates the level of their distress as now family members are faced with a new conundrum: experience the pain of the illness or experience the pain of the treatment. They find themselves overwhelmed with moral distress and a sense of hopelessness.

Forsaken

“Where is the treatment?” is the question family members ask. Once their relatives have been discharged from an acute care hospital where is the community support and treatment? Family members talk about promises made by health care professionals but most of them never materialize. “With the turnstile of case managers he was falling through the cracks...so I called my friend a psychiatric relief worker...she was a “God send.” Family members talked about the need for their ill relative to be in a professional relationship that provides a segue or conduit between their ill relative and all the help that was supposed to come, the community rehabilitation. Family members shared how the social isolation their ill relative experienced was so devastating to observe and stand alongside, that they orchestrated and paid for companions who committed to spending regular leisure time with their ill relative. The sense of despair and forsakenness

family members experience due to the lack of comprehensive treatment and rehabilitation options, is captured in this comment made “they [their ill relative] pay twice...they shouldn’t have to pay because the [treatment] door is closed.”

Reproach

Family members agonized over the pervasiveness of an attitude of reproach and an ideology of culpability extended towards their ill relatives. They sensed that they themselves, as well as their ill relative could and should exercise some control of their illness, take further responsibility for their illness or somehow work harder to cure their illness. The thinking that their family experience is a form of retribution, a punishment from God or alternatively that their suffering is pedagogical; it has been placed before them to teach them something or refine their understanding about something, produced unspeakable pain and a terrible sense of loneliness and isolation. One family member captured it this way, “I didn’t want people looking at him as though he were some social feral...I wanted people to recognize that he was loved and that he was just like everyone else’s son”... “No one checked a little box to get a mental illness. It’s not a short-coming on their part or a result of someone screwing up somewhere...it’s just a bitch and you got dealt a bum hand.”

Torture

When one reads or hears the word ‘torture’ it immediately conjures an image in your mind of the infliction of pain or anguish on the body or mind for the purpose of confession, punishment, intimidation or coercion. It is considered cruel, inhumane and degrading treatment (United Nations High Commissioner for Human Rights, 1984). It was very shocking to me to hear the word ‘torture’ used to describe the experience of

having a relative with mental illness and it warrants further examination. What follows is a short excerpt from my reflections:

This is where my attempts to come to grips with “the flux” really challenge me. Do I have the courage to hear this? Can I stay with it? Can I live in this tension? “Stilling the movement” to allay my fears seems very inviting and in this moment almost more rational. But then where would I be? Stuck? Immovable? (personal journal)

What family members appeared to be speaking to was how the management of their ill relative called them to behave in a way that challenged their previous ways of being and conflicted with their values. Where previously they had ensured that their ill relative had all the necessities of life (food, clothing, money, social contact), they realized that to encourage their ill relative to move towards health and independence they would “no longer being able to support (their ill relative’s) life” in the way they previously had. This meant that their ill relative received from his family no food, no options, “no nothing.” The agony and guilt the family members experienced, thinking that they perpetuated this cruel and inhumane treatment by willfully forcing their ill family member to live in poverty and isolation, was akin to torture. One family member covered her eyes and tearfully said, “I would cry myself to sleep thinking that poor [ill son] was at home starving...I was always afraid that I might push him over the edge and then he would contemplate suicide.” Another family member, a father, quivered as he put it this way, “the hardest thing was that I realized I couldn’t help him ...I had to tell him that he could no longer stay at home... that he couldn’t come home despite the fact that we have four empty bedrooms in our house.” The mental anguish family members reflected in the quotes above almost brought me to tears. Trying to reconcile the dissonance between what they would do in a more normal circumstance and what they feel is in the best

interest of their ill relative is an ongoing battle. Mental illness turns the life the family previously knew upside-down.

Terrified

In their upside-down world, family members are pushed to cope with a huge range of challenging behaviors that are directly or indirectly related to the illness trajectory. The process of accepting the behavior as a symptom of the illness does not necessarily prepare the family for effective management of the behaviors. Constant negotiation and limit setting of behaviors can be exasperating and family members spoke to the level of exhaustion they experienced when managing the symptoms of their ill relative. "I always thought it would get better...she had to get out because we were going to kill each other if she stayed here," is how one family member described her situation. She went on to say, "I'm the one who wears all the dirt all the time. It just got terrible, terrible, terrible." But having a family member live independently posed as many, albeit different, challenges. Juxtaposed were the concern of not knowing how their ill relative was managing from day-to-day and the thought of something going very wrong and nobody following up. Family members indicated that they live with the terrifying knowledge that ultimately they are their ill relatives' 24-hour support system and for many of them, "there is not a lot of room between him [as their ill relative was that day] and going over the edge ... and that is frightening." Family members were terrified of the condition they might find their family member in.

*iii) The Long Term Care and Support Phase**Pervasive*

Having a relative with mental illness predisposes all family members to an inordinate amount of bearing witness, of watching the agony, torment, and anguish of others. If bearing witness of their ill relative's suffering is not enough, family members also witness the effect the illness has on others, such as spouses, siblings, children and other extended family members. Parents tearfully spoke about how their healthy children are robbed of a peaceful and secure home: how they learn to tread lightly, how to cope with chaos and unpredictability of the episodes of illness, and how they inevitably socialize only outside of the family home. Parents shared that their healthy children grieve the loss of their relationship with their ill relative. One family member captures it this way, "he wants to have a relationship with his big brother...similar to ones that his friends do...you know where they go to the bar, have a drink, talk about sports and that sort of thing. So he aches for the brother that he doesn't have...he's hugely worried about him...his heart sinks every time he (his ill relative) calls...it's hard for me to see."

Misunderstood

The lack of understanding and resulting isolation cuts deep. Family members felt that too often the support offered by friends and family was laden with inadvertent judgments, thus over time it was easier not to talk about it at all. When I began writing the findings of this study, I was compelled to accompany my daughter to attend a funeral for an acquaintance of several of my children. He was a brilliant young father who struggled with depression and despite being in treatment, he committed suicide. There was standing room only at the service and the wailing of his family members cut through

my heart and that of others. Those in attendance endured the many well meaning comments filled with assumption and conjecture made by friends and family. The 'celebration' of his life was somber. The service went on for two and a half hours but there was no closure. There was an elephant in the room and nobody could approach it. Then, at a given point his elderly Grandmother slowly made her way to the microphone. She had prepared a few words about her eldest grandson but she was so distraught she could hardly read them. Exhausted and with a very deep sigh, she let her arm, paper in hand, fall and said, "David had a mental illness, he didn't want to die, he just couldn't live anymore." Her final comment was a gift to all those in attendance. She understood. Her grandson had a fatal illness. He didn't kill himself, the illness killed him. There is little compassion or understanding for the notion that the illness caused the death rather than the person who committed suicide. The anguish of unyielding misunderstanding in the midst of their grief renders the family members mute. They feel abandoned. The isolation is profound. His parents and siblings uttered no words, their pain unspeakable. The impact of the Grandmother's final comment was incredible; she had the courage to approach the elephant that everyone was dancing around and it freed those in attendance to be able to really get on with the true celebration of his life.

Grief

Family members talked about never being free from the effects of the illness and therefore they experienced incomplete grief. "It's something you can't get away from"; "there is no end," they said. The tremendous sense of loss family members experience is deep and constant. They described that, as various stages of life pass, their ill relative by the grieving reappears: "He's not going to be who he used to be...I don't even

remembers sometimes what he used to be like...I look at pictures of him...I love him still but I don't like him very much because he's not who he's supposed to be. There's no finality to it." The grief appears to be right beneath the surface of their existence and it rears its head when one least expects it. When a mother cried as she spoke about her sorrow and grief she stated, "I don't often do this (cry about the losses) anymore. You think you are on top of it but unfortunately this is the down side of family, you never get on top of it. I'm on top of the panic...I don't panic anymore but that's because I don't ever look there. Initially it takes you quite a while to figure out that you don't look in certain places because if you, you know, it's not even panic, it's flat out terror, its terrifying so you learn not to look there. There is no advantage in it, it doesn't help you in any way so you learn not to look there." They make valiant academic attempts to accept their life and that of their ill member as it is, from day to day but their emotions betray them. The same mother said, "You can't not look there, it's just there all the time, you can't get away from it." The sorrow and anguish is insurmountable; family members are ensnared by their losses, the suffering is inexorable.

Hopelessness

And as if all that has been discussed is not enough, family members indicated they had no hope. This profound hopelessness appeared to be more painful than anything they had experienced and it deeply impacted me when I realized that several of the family members had spoken to it. What follows is a short excerpt from my reflections:

This is disturbing! Is not the provision of hope foundational to life? Was it was not Cicero, a great Roman orator that proclaimed, "While I live, I hope." Isn't hope the essence of human existence? So how is it that family members' feel hopeless? And have I as a professional in any way contributed to their sense of hopelessness? (personal journal)

Hopelessness for family members appeared multidimensional as it was experienced on many levels. This is in keeping with the work of Schumacher who asserts that “the human being rests on an ontology of not-yet-being and the very internal structure of our being is ordered toward a future” (Smith, 2007, p64). We hope to be able to pass from ‘not-yet-being’ to a place of ‘being –more’ but this possibility was snuffed out upon hearing the diagnosis of their ill relative and realizing in some cases there was no cure for the disease. They shared that interventions such as handcuffing, tasering and isolating stripped their ill relatives of their dignity and produced a sense of hopelessness for the possibility of humane person-centered health care and thus potential self-fulfillment.

Family members spoke of few treatment options and the experience of their ill relative rarely fitting the criteria for these options thus reducing the hope for therapeutic change. They shared that in the times of most significant distress when the symptoms were out of control or when they could not contact a mental health care professional they were overwhelmed with a sense of hopelessness; when they most needed someone to come alongside them “nobody cared.” Family members felt their sense of hope was also undermined by the insensitive or disrespectful manner in which the prognosis of illness was discussed. One family member shivered as she recalled being informed by the psychiatrist that if her son had not met a specific goal in the past year “he likely would never do so.” Comments such as, “he will never marry or have a family,” or, “you will always have to support her (financially),” contributed to a feeling of demoralization, loss of meaning and profound hopelessness for the future. Family members felt they and their ill relative had been “written off.” Thoughts expressed by family members such as “I can’t do anything...I no longer have expectations” removed any sense of agency or

determination (Synder, 2000b) from family members. Furthermore, comments such as, “there are no resources, no pulling together of families...I don’t see anything that gives me hope,” reflects there was no openness or space along their road that affords them room for action (Smith, 2007) and this produces a state of passivity and resignation. Life for family members became hopeless, a joyless process of methodically going through the motions; “it’s like jumping hurdles...you want me to jump through that one...ok I’ll jump.”

Transforming

Despite the challenges that face them, some family members shared that “positive things do come out of this devastating thing [having a relative with mental illness].” They described, that over the years, their philosophy about human life was transformed. They no longer held expectations of “perfect-ness” and had become “tolerant” of diversity in human expression. Their values shifted dramatically. One family member expressed it this way: “we’ve adopted the whole take and you know, he’s not a perfect person and he’s not functioning at a level that you or I would be but he is still loved and pretty marvelous.” Another said, “There is an upside, I would never, ever have learned to be as compassionate and as non-judging (and I am not hugely compassionate or non-judging)...I mean you just can’t.” Family members talked about learning to accept their ill relative as they were, valuing the person rather than that which they accomplished. One of the fathers stated he learned to “have faith that this life that we have isn’t the whole picture and that there is more to us than these physical bodies that we live in.”

Conclusions

Jardine (1998, p.40) says that interpretive inquiry begins with a different sense of 'the given'; it begins in the place where we actually start in being granted or given this incident in the first place. These striking incidents make a claim on us and open up and reveal something to us about our lives together. I have worked with this population for thirty years and it has so enriched my life that I feel indebted to them. I have always been confident that only they carry the key to understanding their suffering. By coming along side them and being present with them as they shared their lived experience we have co-created a deeper meaning of their suffering. Some of the descriptors they used to depict their experience of this phenomenon were not surprising to me; words such as guilt and grief have been common themes in my past dialogues with family members as well as in current and past literature. Others were shocking representations of my worst fears; words such as torture, terror, hopeless, forsaken, betrayed and unbearable provided vivid portrayals of their lived experience. They live suffering; it is intense, pervasive and relentless. In this moment the horizon has opened, the bidding heeded. Despite how foreboding suffering is for even health professionals we can not succumb to feelings of helplessness and avoidance. My contention is that what I have heard is significant and relevant to human beings in general as well as the caring practice of multi-disciplinary mental health professionals.

Effect of Research on the Researcher

The journey has been tremendous and has exceeded my expectations. Over and over again, each step of the way, I stood in awe of the participants who willingly chose to walk with me through their experience. I learned something of the incredible strength

that buds out of weakness. It is very different from the powerfulness of winners in our culture, it is about the ability to totally accept an individual (regardless of their weakness) and truly cherish their person. The strength lies in their ability to surrender their own needs for success and acknowledgement, to empower those that are weak and dependent, those we rarely honor or admire. There is a depth to their strength that evokes a strong guttural emotion but is difficult to put to words. It's something of our shared humanity; you see we are all weak in some way or another. Family members reveal a compassion for 'others' (those that don't fit our culture's neat little boxes) that brought me to my knees. To 'go to that place' again, with me, for the sake of others, was another sacrifice and demonstrated the depth of their courage and strength.

I have learned, that to understand another person or an experience requires much more than listening or being open to hearing. Through the research methodology chosen for this study, I have come to appreciate (and understand) that understanding requires intentional awareness of our embodied response. It calls us to use all that our bodies give us, what we hear, see, touch, think, sense, feel and interpret. I have learned how I have held back that which my body gives me, in fear of not maintaining my professional boundaries. I have experienced a sense of freedom in being encouraged to openly integrate that which constitutes and situates me into my understanding of a phenomenon.

Hermeneutical interpretation of text also affirmed my developing sense that the point of interpretation is not to define a final truth about something but rather to reveal a range of interpretive possibilities. This allows space for multiple meanings rather than a continual search for a truth. Again, this gives the researcher some freedom or movement;

I am a being always becoming. I acknowledge I don't have all the answers but I am willing to look, listen and interact and see what is created.

Implications for Practice

In many ways, one would expect a nursing researcher to draw some conclusions or make some recommendations regarding future nursing practice based on the new understanding gained from an inquiry. However, I find this is particularly challenging. This enquiry set out to *explore the suffering* of family members of people with mental illness, to discover what their suffering was about, to walk about the phenomena, to see and to hear it, to be with it and to feel it, all the time hoping to understand their experience more fully. I wasn't looking for themes that were embedded into the experience of several family members; I was looking to understand the breadth and depth of their life, a life made unique and particular by the experience of mental illness. And of all that was shared between us (the researcher and the family member) some things began to "hang together" and took the form of words which captured something of their life and our mutual understanding. It is difficult to speak or write about this understanding because even the words used to describe their experience may confine the meaning. To take these words and further identify themes or concepts which could guide nursing practice, may be honorably intended but does exactly what this inquiry hoped not to do, box in their experience. Appendix 5 visually depicts my present understanding of the suffering of family members of people with mental illness. You will notice that words have deliberately been captured in different colors, fonts, and size to emphasize the variation in the family experience. I believe this is critical to understanding the needs of the family; each family is different and may experience some or all of what has been

captured in this inquiry. It is therefore essential that when entering a professional relationship with family members of people with mental illness we do not assume to understand their needs but allow them to direct us in mapping out how we can respectfully care for them.

How I would take up nursing practice thus relates not to what I might do but rather how I would be with family members. I need to invite family members into a safe space, where I am very intentional about suspending or minimizing my judgment or assumption. A safe place in which they are free to share their experience, as it has been or is, for them (not as I might assume it to be). I need to acknowledge their suffering and then have the courage to commit to walking along side them, to endure with them, not healing, not curing, but facing the reality of their powerlessness, for as long as it takes for them to see a glimmer of hope.

In my role as a nurse educator, the importance of student nurses acknowledging and understanding the uniqueness of each person they care for has been affirmed. Besides the scientific knowledge students require in preparation for nursing practice, they must develop strong interpersonal skills that will assist them in initiating and maintaining authentic professional relationships with an ever changing population of people. Furthermore, if we are truly committed to walking along side our clients, student nurses would benefit from the development of a working understanding of many different philosophies, perspectives and models of health care which they could draw from in providing care for their clients. I sometimes wonder whether implicit in being somewhat eclectic in our practice is what defines our profession and reflects our uniqueness.

More generally, as health care professionals, we need to understand the suffering of family members of people with mental illness and acknowledge that it is real and unique to every family member. We need to be totally present with family members, in a place where they can freely express their emotions, and we must be willing to hear their cries and the words spoken and unspoken. This calls for an unhurried approach to clients and their family members and a commitment to being in professional relationship for as long as they need. It begs us to move away from prescriptive or standardized care to individualized and holistic care directed by the family members. This kind of care demands a broad array of mental health services with flexible access to meet the diverse needs of family members. Careful examination of work practices, through a process of reflexivity (Doane & Varcoe, 2005), will facilitate the identification of approaches that do not meet the needs of the family.

But research does not stop after analysis or interpretation; on the contrary, it entices you to continue wondering, exploring and challenging. The circle on the surface of the flux continues to move (Caputo 1987) and in many ways has opened more questions than answers. Questions such as how does one care for family members that are living suffering? What is the essence and meaning of enduring suffering for families confronted with mental illness? Is there a correlation between the degree of suffering family members experience and the acuteness of the illness of their relative? How can the approach to caring for a person with mental illness reduce the suffering of family members? What do we understand of our human response to the suffering of family members (in the role of a health care professional, as a member of a family, or community)? It is time to fully acknowledge the degree of suffering experienced by

family members living with mental illness and then listen again and again as they help us identify what they may need.

“What did you want to say”, the interpreter asks the poet. And the poet replies, “I wanted to say precisely what I said; because it is what I saw.”

Rubem Alves

References

- Blackwell, T., Strohmer, D., Belcas, E. & Burton, K. (2002). Ethics in rehabilitation counsellor supervision. *Rehabilitation Counselling Bulletin*, 45:4, 240-247.
- Canadian Nurses Association. (2002). *Advanced nursing practice: A national framework*. Ottawa: Author.
- Caputo, J. D., (1987). *Radical hermeneutics; Repetition, deconstruction, and the hermeneutic project*. Bloomington and Indianapolis, IN: Indiana University Press.
- Cassell, E.J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine* 306, 639-645.
- Cassell, E.J. (1991). *The nature of suffering*. New York, NY: Oxford University Press.
- Cuijpers, P. (1999). The effects of family interventions on relatives' burden: A meta-analysis. *Journal of Mental Health* 8(3), 275-285.
- Dewar, A.L. & Morse, J.M. (2005). Unbearable incidents: failure to endure the experience of illness. *Journal of Advanced Nursing* 22: p. 957-964.
- Doane, G. & Varcoe, C. (2005). *Family nursing as relational inquiry*, Philadelphia, PA: Lippincott Williams & Wilkins.
- Fleming, V., Gaidys, U., & Robb, Y. (2003). Hermeneutic research in nursing: developing a Gadamerian-based research method. *Nursing Inquiry* 10(2), p.113-120.
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. In P.L. Munhall (Ed.), *Nursing research* (p.555-568). Mississauga, ONT: Jones & Bartlett.

- Francell, C., Conn, V., & Gray, D. (1988). Families' perceptions of burden of care for chronic mentally ill relatives. *Hospital and Community Psychiatry*, 39, 1296-1300.
- Frank, A. (1995). *At the will of body: Reflections on illness*. Chicago, Ill: The University of Chicago Press.
- Gadamer, H. (1989). *Truth and Method*. New York: Crossroad.
- Gillis, A. & Jackson, W. (2002). *Research for nurses: Methods and interpretation*. Philadelphia, PA: F.A. Davis Company.
- Hamric, A.B., Spross, J.A. & Hanson, C.M. (Eds.). (1996). *Advanced nursing practice: An integrative approach* (3rd ed., p. 109-139). St. Louis, Missouri: Elsevier Saunders.
- Hanson, S. (2001). *Family health care nursing: Theory, practice and research* (2nd ed.). Philadelphia: F.A. Davis.
- Hartrick, G. (2002). Beyond interpersonal communication: The significance of relationship in health promoting practice. In L. Young & V. Hayes (Eds.), *Transforming health promotion practice. Concepts, issues and applications*. p.49-58. Philadelphia: F.A. Davis
- Hatfield, A.B. & Lefley, H.P. (2005). Future involvement of siblings in the lives of persons with mental illness. *Community Mental Health Journal* 41(3), p.327-338.
- Hatfield, A.B. (1997). Working collaboratively with families. *Social Work Health Care* 25: 77-85.
- Health Canada. (2006). *The human face of mental health and mental illness in Canada*. Ottawa: Author.

- Heidegger, M. (1971). *Poetry, language, thought*. Harper and Row: New York: Perennial.
- James, T. & Platzer, H. (1999). Ethical consideration in qualitative research with vulnerable groups: Exploring lesbians' and gay men's experiences of health care- a personal perspective. *Nursing Ethics*, 6 (1) 73-81.
- Johnson, P. A. (2000). *On Gadamer*. Belmont: Wadsworth.
- Jardine, D. (1998). The fecundity of the individual case: Considerations of the pedagogic heart of interpretive work. In D. Jardine (Ed.), *To Dwell with a boundless heart: Essays in curricular theory, hermeneutics and ecological imagination*. (p.33-51). New York: Peter Lang.
- Joubert, N. & Stephens T., (2001). The economic burden of mental health problems in Canada. *Chronic Diseases in Canada*, 22(01). Retrieved September 24, 2006 from http://www.phac-aspc.gc.ca/publicat/cdic-mcc/22-1/d_e.html.
- Koch, T. & Harrington, A. (1998). Reconceptualizing rigor: The case for reflexivity. In C. McDonald (Ed.), *Phenomenological and hermeneutic approaches to inquiry*. Victoria, BC: University of Victoria School of Nursing.
- Kreisman, D., & Joy, V. (1974). Family response to the mental illness of a relative: A review of the literature. *Schizophrenia Bulletin*, 10, 34-57
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. CA: Sage.
- Lefley, H. (1987). Aging parents as care givers of mentally ill adult children: An emerging problem. *Hospital and Community Psychiatry*, 38, 1063-1070.

- Lehman, A.F., & Steinwachs, D., (1998). Patterns of usual care for schizophrenia. *Schizophrenia Bulletin*, 24(1), 11-20.
- Lincoln, Y.S. & Guba, E.G. (1985). Naturalist inquiry. In P.L. Munhall (Ed.), *Nursing research* (p.555-568). Mississauga, ONT: Jones & Bartlett.
- Marsh, D. (1992). *Families and mental illness: New directions in professional practice*. New York: Praeger.
- Marsh, D. (1998). *Serious Mental Illness and the Family*. New York, NY: John Wiley & Sons Inc.
- Marsh, D., Appleby, N., Dickens, R., Owens, M., & Young, N. (1993). Anguished voices: Impact of mental illness on siblings and children. *Innovations and Research*, 2(2), p. 25-34.
- McDonald, C. (2005). *Phenomenological and Hermeneutic Approaches to Inquiry*. Victoria, BC: University of Victoria Distance Education Services.
- Merleau-Ponty, M. (1962). *The primacy of perception*. (J.Edie, Trans.) Evanston: Northwestern University Press.
- Milliken, P.J. & Rodney, P.A. (2003). Parents as caregivers for children with schizophrenia: Moral dilemmas and moral agency. *Issues in Mental Health Nursing*, 24: p.757-773.
- Morris, D.B. (2000). How to speak postmodern: Medicine, illness and cultural change. *Hastings Center Report* (6), 7-16.
- Morse, J.M. (2000). Responding to the cues of suffering. *Health Care for Women International* 21:1-9.

- Morse, J.M. (2001). Toward a praxis theory of suffering. *Advanced Nursing Science* 24(1), p.47-59.
- Morse, J.M. (2003). The significance of standards. In P.L. Munhall (Ed.), *Nursing research* (p.555-568). Mississauga, ONT: Jones & Bartlett.
- Nouwen, H., McNeill, D., & Morrison, D. (1982). *Compassion: A reflection on the Christian life*. New York, NY: Doubleday, Random House Inc.
- O'Connell, K.L. (2006). Needs of families affected by mental illness. *Journal of Psychosocial Nursing*, 44(3), p. 40-48.
- Oldridge, M., & Hughes, I. (1992). Psychological well-being in families with a member suffering from schizophrenia. *British Journal of Psychiatry*, 161, 249-251.
- Östman, M. & Hansson, L. (2000). Stigma by association: Psychological factors in relatives of people with mental illness. *British Journal of Psychiatry and Psychiatric Epidemiology* 34, 157-165.
- Patton, M. (2002). *Qualitative Research and Evaluation Methods*. Thousand Oaks, CA: Sage Publications.
- Polit, D., & Beck, C. (2004). *Nursing research: Principles and methods*. Philadelphia, PA: Lippincott Williams & Wilkins.
- Pomeroy, E., Trainor, J., & Pape, B. (2001). Citizens shaping policy: The Canadian mental health association's framework for support project. *Canadian Psychology* 43(1), 11-20.
- Rose, L., Mallinson, R., & Walton-Moss, B. (2004). Barriers to family care in psychiatric settings. *Journal of Nursing Scholarship*, First quarter.

- Rubin, H.J. & Rubin I.S. (1995). Qualitative interviewing: The art of hearing data. In M. Patton, (2002). *Qualitative Research and Evaluation Methods*. Thousand Oaks, CA: Sage Publications.
- Sacks, J.L. & Nelson, J.P. (2007). A theory of nonphysical suffering and trust in hospice patients. *Qualitative Health Research* 17(5) p.275-689.
- Sandelowski, M. & Barrosa, J. (2002), Reading qualitative studies. *International Journal of Qualitative Methods*. 1(1), 1-47.
- Sareen, J., Cox, B., Afifi, T., Yu, B., & Stein, M. (2005). Mental health service use in a nationally representative Canadian survey. *Canadian Journal of Psychiatry*, 50(12), 753- 761.
- Saunders, J. (1999). Family functioning in families providing care for a family member with schizophrenia. *Issues in Mental Health Nursing*, 20(2), 95-113.
- Saunders, J. (2003). Families living with severe mental illness: A literature review. *Issues in Mental Health Nursing* 2, 175-198.
- Simmington, J.A. (2004). Ethics for an evolving spirituality. In J. Storch, P. Rodney & R. Starzomski (Eds.). *Toward a moral horizon: Nursing ethics for leadership and practice* (p. 465-484). Toronto: Pearson Education Canada Inc.
- Smith, D.G. (1994). *Pedagon: Meditations on pedagogy and culture*. Makyō Press: Bragg Creek.
- Smith, D.L. (2007). A phenomenological reflection on the experience of hope. *The Humanistic Psychologist*, 35(1), 81-104.
- Snyder, C.R. (2000b). The past and possible futures of hope. *Journal of Social and Clinical Psychology*, 19, 11-28.

- Spaniol, L., Zippie, A., Marsh, D., Finley, L. (2000). *The role of the Family in Psychiatric Rehabilitation*. Boston, MA: Boston Center for Psychiatric Rehabilitation.
- Speziale, H.J., & Carpenter, D. (2003). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia, PA: Lippincott Williams & Wilkins.
- Thompson, E., & Doll, W. (1982). The burden of families coping with the mentally ill: An invisible crisis. *Family Relations*, 31, 379-388.
- United Nations High Commissioner for Human Rights, (1984). United Nations convention against torture. Part 1, Article 1. Retrieved November 13, 2007 from <http://www2.ohchr.org/english/law/cat/htm>
- van Manen, M. (2003). *Researching lived experience: Human science for an action sensitive pedagogy* (3rd ed.). London, ON: Althouse Press.
- World Health Organization, (2004). Prevalence, severity and unmet need for treatment of mental disorders. *Journal of American Medicine Association*, 29, 2590.
- Wright, L.M., & Leahey, M. (1994). *Nurses and families: A guide to assessment and intervention* (2nd edition). Philadelphia; F. A. Davis.

APPENDIX 1

Suffering of Families of the Mentally Ill: A Hermeneutical Study

NEWSLETTER ADVERTISEMENT FOR CAPITAL MENTAL HEALTH
ASSOCIATION AND THE BC SCHIZOPHRENIA SOCIETY

RESEARCH PARTICIPANTS NEEDED!!

Do you have a family member who is living with mental illness? Would you be willing to talk with a researcher about your experience?

A qualitative study exploring the family experience of mental illness is being conducted by Wilma van Wiltenburg RN, BSN, a graduate student in the School of Nursing, University of Victoria.

Participation in the study would involve a conversation/interview of two hours. If you are interested or have questions please contact the researcher: Wilma van Wiltenburg at (250) 370-3290 or wiltenburg@telus.net

APPENDIX 2

Suffering of Families of the Mentally Ill: A Hermeneutical Study

CONSENT

You are being invited to participate in a study entitled Suffering of Families of the Mentally Ill: A Hermeneutical Study that is being conducted by Wilma van Wiltenburg.

Wilma van Wiltenburg is a graduate student in the department of Nursing at the University of Victoria and you may contact her if you have further questions by emailing (wiltenburg@telus.net) or by telephone (250-370-3290).

As a graduate student, I am required to conduct research as part of the requirements for a Master's degree in Science of Nursing. It is being conducted under the supervision of Dr. Carol McDonald. You may contact my supervisor at (250) 472-5280.

The purpose of this research project is to gain a greater understanding of the suffering of families dealing with mental illness. Research of this type is important because it may help us better understand what underlies the suffering of families of the mentally ill. New understanding of the family experience of mental illness may assist in the development of improved approaches to treatment and support of the family and result in a reduction in suffering experienced by the family and a benefit to both participants and society in general.

You are being asked to participate in this study because you are a family member of a person suffering mental illness and we would like to hear your account of what that means in your life. The study will attempt to hear the stories of ten different families. If you agree to voluntarily participate in this research, your participation will include one two hour interview and to minimize any inconvenience to you the interview can take place in your home or at my office at a time which is works best for you. The researcher will take written notes and/or audio tape the interview. The data will be transcribed by a third party and will be analyzed by the researcher. The findings will be documented in a written report which will be available to participants.

By participating in this research you may experience an emotional response to past experiences or the opening of sensitive wounds. To prevent or to deal with these risks the following steps will be taken:

- all questions will be respectful, appropriate and sensitively presented
- participants will be encouraged to answer only those questions they feel they are able to
- if the participant becomes upset during any part of the interview, the researcher will be pause, reschedule or end the interview altogether. The researcher will debrief or call on

another person to support the participant. The researcher will remain with the participant until the person arrives.

- If necessary the researcher will refer the participant to counselling agency to deal with the emotional response.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be used only with your permission.

In terms of protecting your anonymity, you will have face-to-face contact with the researcher but you will decide what personal identifiable information you wish to extend to the researcher. The contact person at the agency who referred you to the researcher and the researcher will be the only people aware of your participation in the study. Further confidentiality of your involvement in the study and the confidentiality of the data collected will be protected by securing all data with a password or storing it in a locked cabinet. Data will only be used for its intended purpose and reporting data will involve purposeful masking of bibliographical details that may identify a participant or their ill family member. Results of this study will be shared with others by means of a thesis. Data from this study will be deleted, shredded or erased five years following the completion of the study.

Individuals that may be contacted regarding this study include the researcher and her supervisor (refer to information at the beginning of consent form). In addition to being able to contact the researcher and supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4545) or Peter Kirk Director of Research and Academic Development at the Vancouver Island Health Authority (250-370-8620)

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

Name of Participant

Signature of Participant

Name of Researcher

Signature of Researcher

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

APPENDIX 3

Suffering of Families of the Mentally Ill: A Hermeneutical Study

TRANSCRIBER CONFIDENTIALITY AGREEMENT

Researchers and research assistants have a legal and ethical responsibility to safeguard the privacy of all study participants and to protect the confidentiality of their health information. By signing this document, I understand the following:

1. I agree not to disclose confidential information to others (including family or friends).
2. I agree not to discuss confidential information where others can overhear the conversation.
3. I agree not to make inquiries for others who do not have access authority.
4. I agree to keep my computer password to myself. I will log off when I leave a workstation which contains confidential information.
5. I agree not to add to, transfer or delete any data.

I have read the above agreement and agree to hold in confidence all information or data related to this study.

Signature of Transcriber

Date

PRINT NAME

APPENDIX 4

A Hermeneutical Study Suffering of Families of the Mentally Ill:

INTERVIEW QUESTIONS

1. How would you like me to address you, by your first name or a pseudonym?
2. How long has your family been dealing with mental illness? (How long ago did you become aware that your family member was struggling with mental illness? How long ago was your family member diagnosed?)
3. I am interested in developing a deeper understanding of the suffering of family members of people with mental illness. Could you share with me your experience of suffering? What stands out for you regarding this?
4. What have been the challenges for your family in coping with your ill family member?
5. Have there been positive aspects of your family experience of mental illness? Could you speak to these please?
6. Has your family experience of mental illness affected your health? How?
7. In your experience, what has helped your family deal with your family member suffering mental illness?
8. What did you not experience that you feel might have helped your family deal with your ill family member?
9. If you could express your concerns for families dealing with mental illness to a senior health care planner, what would you say?

Transforming

Terrified

Lost

betrayal

Misunderstood

Hopelessness

Disconnected

Torture

Unbearable

Pervasive

Unsuspecting

forsaken

Grief

Reproach

Guilt

CONFLICTED