My work is to inhabit the silences with which I have lived and fill them with myself until they have the sounds of brightest day and the loudest thunder.

(Lorde, 1980, p. 46)

First Episode Psychosis: The Experience of Parent Caregivers

by

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DEDICATION

To the silent heroes that live among us and to the loving families that support their recovery, may we all hold the hope that their heroism and courage might be revealed and embraced without prejudice. May love and understanding eventually eliminate stigma.

ABSTRACT

Psychosis is a serious but treatable psychiatric disorder, characterized by changes in perceptions, thoughts, feelings, beliefs and behaviours. Each year in Canada, as many as 10,000 young people between the ages of 15 and 30 years of age, may experience their first episode of psychosis (CMHA, 2005). Certainly the emergence of psychotic illness is a distressing and confusing time, not only for young persons experiencing these perplexing changes but also for their parents. The family and in particular the parents, play a critical role in early intervention for psychosis, both as a vehicle for early identification and treatment, and as a supportive context for recovery.

An interpretive phenomenological inquiry was undertaken to answer the primary research question: How do parent caregivers experience first episode psychosis in their young adult child? The purpose of this study was twofold: 1) to understand the lived experience of parents involved in caregiving for a young son or daughter who is experiencing first episode psychosis (FEP) and 2) to utilize the research Pathway and Hermeneutical Principles of Research (HPR) originally formulated, tested and amplified by Dr. Sherrill Conroy (2003) as the guiding method for accomplishing research predicated on Heideggerian philosophy.

In this Heideggerian interpretive phenomenological study, the meaning and experiences of nine parent caregivers with a young adult son or daughter with first episode psychosis were explored. Data were collected through conversations with mothers and fathers whose young adult children were involved with a specialized early psychosis intervention program in southwest Ontario. The nature of the meaning of the parent caregivers' experience led to uncovering four distinct stories: a story of Protection; a story of Loss; a story of Stigma; and a final story of Enduring Love. The findings of this inquiry help to illuminate and bring awareness to what it means to be parents of a young adult child newly diagnosed with psychotic illness. I illuminate how healthcare providers and nurses in particular can have more discretion, insight and discernment in clinical approaches with parent and family initiatives within early psychosis intervention programs. The findings of this inquiry may also serve to shape future policies, which will recognize and affirm the strengths and resilient capacities of parent caregivers.

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And finally at the risk of being perceived of as potentially silly, I must also acknowledge the faithfulness and accompaniment of my old dog “Charlie”. I may have rescued you but in another way, you consistently rescued me by insisting I keep your schedule and take time out for a walk or a car ride.

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CHAPTER ONE

As little as we know of illness, we know even less of care. As much as the ill person's experience is denied, the caregivers experience is denied even more

Arthur Frank 1997

Commencing a Journey

I begin this chapter with an overview of the context and background that frames the genesis of this study. Following this, I articulate the aim of this inquiry, identify the phenomenon of interest, and the accompanying guiding research question. Also included in this chapter is a discussion around the selected research approach, including identification of my own perspectives and assumptions as researcher. This chapter concludes with a discussion that articulates the rationale and significance of this inquiry.

Context of the Inquiry

Not so long ago, the onset of a serious mental illness would elicit feelings of hopelessness and the inevitability of cognitive and social decline. When I began my nursing career in the mid-1970s, I worked in a day treatment program with young people who were newly diagnosed with illnesses like schizophrenia, bipolar disorder or major depression. At the time these young people were dubbed "young adult chronics" or "YAC's" for short. The abject insensitivity of this short acronym said it all. There was no hope of a normal life when it was predetermined that you were “chronic” from the onset of illness. Expectations for recovery were minimal. It was a dreadful thing, to see these young people, (many of whom were my own age at the time) return from what was typically a very long hospitalization, of at least a couple of months, and try to resume their lives. There was a clear message to these young individuals, and that was to: settle into a routine, take their very sedating medicine and learn a handicraft. Leatherwork, macramé and copper tooling were popular crafts at the time. The patients I worked with were either living in boarding houses and group homes for the mentally ill or if they were lucky, they returned to live with parents. The return to live with parents however was regarded by most mental health professionals with some suspicion. Parents were not perceived to be ‘objective’ enough to provide appropriate care for their son or daughter and were simply assumed to have a negative impact upon mental stability. In the 1970s though, no one was talking about empowerment or recovery and there was little if any real concern for the impact of a young person’s illness upon his or her parents.

During this era I worked in a program that had its mission statement, “to maintain and if possible improve functioning”. A patient’s educational pursuits were put on hold indefinitely or abandoned completely. Vocational aspirations were also dismissed as too stressful and notions of marriage and family were deemed the result of a patient’s lack of insight. This approach was one of simply maintaining, and “if possible”, supporting an adjustment to a lower stress lifestyle of living the life of a young adult chronic. As a new nurse, it was a difficult first job. I held more hope for these individuals than these categorizations could indicate but I also had greater aspirations for myself than to be a custodian of the hopeless. I was not convinced that these young persons should settle into chronicity without a fight. When I reflect back on this now, I cringe at the hopeless messages provided to these individuals and by association their parents.

Psychologist and American psychiatric disability advocate, Patricia Deegan (1996), describes from her own personal experience what it was like to receive a psychiatric diagnosis of serious mental illness in the 1970s.

> I was 18 years old, I asked the psychiatrist I was working with,” What’s wrong with me?” He said, “You have a disease called chronic schizophrenia. It is a disease that is like diabetes. If you take your medications for the rest of your life, and avoid stress then maybe you can cope. (Deegan, 1996. p. 3)

Deegan describes the impact of these words. The very process of being given a diagnostic label crushed her sense of future. Her hopes and dreams were unceremoniously stolen from her and replaced with a hopeless and doom-filled prognosis. She eloquently describes feeling the weight of these words, “crushing” her already fragile hopes, dreams and aspirations for the future. For Deegan, the haunting memory of this time does not fade. Her psychiatrist failed to see the young Deegan as a young person with possibilities; instead he saw her as a ‘chronic illness’ and provided her with little if any hope. Her family, though, were given an even more negative prediction of her future potential (Personal Communication, 2006).

Oftentimes my own professional memories of this period of psychiatric treatment remain repulsive and disturbingly vivid. In the late 1970s, I naively participated in practices that I believe now in hindsight to be less than caring practices had more to do with social control than with being therapeutic. It is interesting to reflect upon what was once considered best practice in light of new research. It was always so difficult to explain the paralyzing sedation caused by the high dosages of prescribed major tranquilizers to desperately worried families. I still recall the fear and sadness on the parent’s faces. To the parents of the 1970s, their young adult child was perceived as forever ill. The onset of mental illness was not just something experienced only by the family member who embodied the illness. The first episode of mental illness was a family-wide experience. All family members were seemingly affected by its presence, but the onset of serious mental illness in a loved young adult child had a special impact upon parents. No doubt the commonly held perceptions of likelihood of chronicity heightened this impact.

New early treatment approaches promise enhanced recovery

Thankfully, more than thirty years later the initial treatments for serious mental illness are much more artful and the resulting prognosis from an episode of psychosis is resoundingly more hopeful. Psychosis is a serious but treatable psychiatric disorder, characterized by changes in perceptions, thoughts, feelings, beliefs and behaviours. Each year in Canada, as many as 10,000 young people between the ages of 15 and 30 years of age, may experience their first episode of psychosis (FEP) (CMHA, 2005). While it is difficult to ascertain the cause of psychosis the first time it occurs, it is most often associated with illnesses like schizophrenia, depression and bipolar disorder. Although psychosis can happen to anyone, more often than not psychotic symptoms develop during late adolescence and early adulthood. Certainly the emergence of psychotic illness is a distressing and confusing time, not only for young people experiencing these changes but also for their parents. In fact, most young adults who experience their first episode of psychosis are still residing with their families (Addington & Gleeson, 2003). Thus, the family and particularly the parents, play a critical role in early intervention for psychosis, both for early identification, encouraging early treatment, and for enhancing recovery.

Within the past decade or so there has been renewed energy in the field of psychiatry and mental health in response to a growing body of evidence that supports the notion that early intervention for those with emerging psychotic disorder leads to significantly better recovery outcomes. The main premise of Early Psychosis Intervention (EPI) is simple: to intervene in a comprehensive way as quickly as possible following the onset of illness. There is growing recognition that early intervention strategies can help young people experiencing a first episode of psychosis to return to their usual or former level of coping with life. (Birchwood, McGorry, & Jackson, 1997; McGorry, Edwards, Mihalopoulos, Harrigan, & Jackson, 1996). Results from international early psychosis research promises better outcomes for the next generation of young persons who experience psychosis and potentially fewer burdens experienced by their families. As such, a proliferation of specialty treatment programs has evolved across Canada and globally to meet the needs of those with emergent psychosis. The government of Ontario, for example, spent an unprecedented $23 million in 2005 to ensure that regional early intervention services be developed (Ontario Ministry of Health and Long Term Care, 2005). The current provincial commitment to early intervention is remarkably hopeful. The message for individual sufferers and by extension their parents, is now one of cautious optimism and empowerment. This requires that mental health care providers look beyond mere recognition of illness and to wholeheartedly encounter the human being and family as they come for professional help.

First Episode Psychosis: The experience of parents

The basic tenets of early intervention place families in a central role in identifying symptoms early and, once identified, robustly supporting the recovery efforts of an ill relative. This requires programs, such as those mandated by the Ontario early psychosis policy framework, to create a collaborative family-centered atmosphere. Programs must fully, respect and re-affirm the important role assumed by parents since birth and now through the earliest stages of assessment and treatment initiation for early psychosis. This is seemingly the first time that government is fully supporting the caregiving role assumed by family members in a mentally ill relative’s recovery has been clearly articulated by the development of a proactive policy framework and backed up by specific funding for targeted family supports (CMHA, 2005; FMHA, 2006; Ministry of Health and Long Term Care, 2005; OWG, 2004).

The provincial Ontario policy framework documented an overall goal to proactively provide families with what they need from the very first moments they enter the mental health care system, thus setting the stage for successful partnerships over the long term and potentially reducing the occurrence of caregiver burden. In Ontario, a comprehensive early intervention in psychosis program must focus on:

- Reducing the duration of untreated psychosis through early and appropriate detection and response, thereby potentially reducing the severity of illness;
- Minimizing the disruption in the lives of young people who experience psychosis such that educational, vocational, social and other roles can be maintained; and
- Minimizing the societal impact of psychosis including reducing demands in other areas of the mental health, health and social service systems and reducing disruption in the lives of families (2011 EPI Program Standards, Ontario. p.7).

Just as those with an emergent psychotic disorder are provided with comprehensive interventions as soon as possible after illness onset, their parents must also have access to supports and interventions, which affirm their own wellbeing and provide them with the skills and knowledge to be effective and successful in their caregiving efforts. However, the funding for early intervention programs in Ontario has been provided in advance of any research, which captures just what this caregiving experience means to parents. To date, the lived experience of parents at this early stage of caregiving has not been explored. However, such an inquiry is an essential first step in order to create supports and resources that will best meet the needs of these new family caregivers. Additionally, due to enhancements in new treatments and approaches, current parent caregivers begin their role within a much more hopeful context and one that thoroughly embraces notions of recovery. While the stress and perceived burden of caregiving for a family member with chronic and persistent symptoms of mental illness has been extensively studied, there has been almost no research focusing upon the initial experience of parents at the onset stage of their son or daughter's psychotic illness. In the absence of qualitative research that helps to elucidate the lived experiences of early psychosis parental caregivers, there is the potential to simply reinforce the prevailing status quo for family support and/or education while completely missing this unique opportunity to redesign services by tailoring interventions and supports with the expressed needs of parent caregivers in mind. Any new service which fails to be more responsive to recovering clients and their families, will simply continue to spread the burden of suffering (Jones, 2005).

There is a need for nurses and other mental health professionals to better understand the parent caregiving experience resulting from the emergence of a first episode of acute psychotic illness. By understanding the lived experience of caregiving parents, we may come to know more about its meaning and how best to support their needs. Only then, can we hope to develop practical, appropriate and acceptable supports, which work to create family-friendly services. Mental health nurses are in pivotal roles to both strengthen family coping and affirm the important role of parents at this early stage of engagement with treatment.

Aim of this Inquiry

The aim of this phenomenological inquiry was to offer an account of what it means for a parent caregiver to experience the emergent psychosis of their young adult son or daughter. The synthesis of findings provides new insights. Hopefully these insights will serve to inform further research and the subsequent development of pro-active and health promoting parent-supports. The results of this inquiry will help to illuminate and bring awareness to what it mean to be parents of a young adult child newly diagnosed with psychotic illness. In this dissertation, I illuminate how healthcare providers, and nurses in particular can have more discretion, insight and discernment in clinical approaches and family initiatives within the Early Psychosis Intervention (EPI) network. The findings of this inquiry may also serve to shape future policies, which recognize and affirm the strengths and resilient capacities of parent caregivers.

Phenomenon of Interest

The phenomenon of interest was the lived experience of parent caregivers in response to first episode psychosis in their young adult son or daughter. Parental caregiving in the beginning stages of psychotic illness is a unique human experience. Parent caregivers, through their personal knowledge and the meanings that they attribute to their existence as caregivers, are fully able to describe the nature and significance of this experience. This research provides a forum for them to be heard.

Coming-to-the-question

My coming to this question was at least thirty years in genesis. Gadamer (1960/1989) suggests, the *coming-to-the-question* is a process of being taken to task on something, becoming more focused and disturbed, and then being opened to new possibilities that move beyond the initial breadth of the question. To question then, according to Gadamer, “is to open up possibilities and keep them open” (p. 299). It was the notion of being open and opened up to the lived experience of parent caregivers that motivated this inquiry. Ultimately, as described by Munhall (1994), I endeavoured to live the phenomenological question, “what is being?” Attentiveness to the everydayness of the experiences of parent caregivers was essential in determining the meaning of their being. To accomplish this I assumed a phenomenological attitude, which meant I had to listen, to hear, to see the caregiving phenomenon and be open to it wherever it appeared. A Heideggerian interpretive phenomenological approach was therefore employed to answer the primary research question: How is first episode psychosis experienced by parent caregivers of young adults with emergent psychotic illness? Heideggerian phenomenology offers guidance in the development of knowledge about such human experiences.

This qualitative interpretive method is considered appropriate because very little is known about the initial phase of caregiving among parents of young adults with FEP. Gleaning an understanding of the lived experience of parent caregivers can point future researchers in directions that are important to caregivers rather than focusing on what professional care providers or researchers deem important. As such it was advantageous to use an interpretive phenomenological approach to explore the lived experience as understood by the parents. This approach takes into consideration and values the social, cultural and historical world of the individual parents as well as attempting to uncover what may be taken for granted in the caregiving experience. In this case, interpretive phenomenology moves beyond description of the lived experience to delve into the meaning of being a parent caregiver to a son or daughter with first episode psychosis.

My Situated Context

During the early years of my career, I approached my research from a purely scientific or positivist worldview. These experiences were helpful in identifying measures of perceived stress, anxiety, depression or levels of expressed emotion, for example, through using reliable measurement tools with parent caregivers of young adults with schizophrenia. These studies used statistical procedures to make generalizations about the degree to which parent caregivers universally experienced these events. Although interesting at the time, this focus of research failed to help me fully understand the particularities of each parents' lived experience. However, the most interesting data I gleaned was not from the standardized measures; rather, it was from the opportunity I had as a research associate on the clinical team, to interact with and hear the stories of family caregiving as told to me by the parents who agreed to participate in the studies. It seemed to me that there was so much more to the parental experience of caregiving, so much more than could be adequately described or captured by the reporting of reductionist-grouped data.

Lost within this early research were the poignant stories as told by parents as they struggled to come to accept the illness and eventual diagnosis of their son or daughter and all the social and familial implications. Perhaps most distressing to me were my research team experiences where I was directed to rate individual parents' status with respect to a poorly defined and even more poorly conceptualized concept called expressed emotion. Expressed emotion is the critical, hostile, and emotionally over-involved attitude that relatives have toward a family member with a psychiatric disorder. Expressed emotion is a rating of either 'high' or 'low', which is decided by an interview known as the Five Minute Speech Sample (Magana, Goldstein, Karno, Miklovitz, Jenkins & Falloon, 1986). On the basis of a very brief audio taped speech sample, parents were rated as either recovery-enhancing parents (low in expressed emotion, i.e., not over involved, warm and understanding) or relapse-producing parents (i.e. high expressed emotion, meaning over-involved, intrusive and highly critical). At the time I felt very uncomfortable with this dichotomous measurement of parents and felt particularly sick at heart at the disposal of what I felt was the richest data of all: the tape recorded spoken narratives as told by the parents. To me, the interview tapes were a concrete tribute to the bravery and strength it takes to accompany a loved one on a recovery journey back from mental illness.

The speech samples frequently told the stories of stigma, of self-blaming and the potential for lost hopes and dreams. However, other speech samples described courageous efforts to maintain respectful and loving relationships under situations of considerable adversity. Others described the enduring although difficult commitment of parents to a mentally ill loved one and the impact of one family members' suffering upon all who held the individual dear. The physical act of erasing these tapes, as was required following the data analysis, created a palpable tension within me. I struggled with my own feelings of guilt and felt thoroughly unsettled. Upon reflection, I had concerns that I had failed to recognize the suffering, or provide comfort to these families and most of all had not appropriately respected or honoured their participation. I never again agreed to rate expressed emotion. This became an enduring ethical stance on my part and is reflected in this present research commitment to better understand the parent caregivers' lived experiences. My goal was to illuminate the knowledge that remained covered, and yet to be discovered. My living the research question as Munhall (1994) suggests, required attentiveness to the meaning of the parental caregiving experience.

Rationale and Significance of the Study

As previously noted, the motivation for this study emanated from my desire as a nurse to uncover ways to encourage and help FEP parent caregivers to be successful in this new and potentially stressful role. Parents of young adults with emergent psychosis are in an important position to support and encourage recovery efforts. New intervention guidelines recommend that families be provided with timely and proactive supports to identify and modify potentially burdensome aspects of parental caregiving role. Understanding more about the lived experience of FEP parent caregivers seemed a natural first step to provide insights that may assist in identifying currently unmet or unacknowledged parent needs. This inquiry offers a text that uncovers ways to understand the parents' lived experience and perhaps identify resilience-enhancing coping strategies. Conceivably, by understanding needs and acting upon these, at the early stages of transition to caregiving, overall family resilience might be enhanced. Only by understanding how to best support the needs of caregiving parents can nurses and other health care professionals accurately develop practical, appropriate and acceptable supports, with the goal of creating family focused services. This research provides important knowledge, which informs both health and social policies. The findings also further contribute to the body of knowledge about Heideggerian-based methodology by having utilized Conroy's (2003) Pathways for Interpretive Phenomenology and her Hermeneutical Principles for Research in approaching the conversations and interpretive synthesis.

My Foundational Assumptions

It is important to note that incorporated into this inquiry are three primary assumptions. These assumptions stem from my own personal experience as a family caregiver and from my clinical experiences in working with the parents of those with emergent psychosis. The first assumption is that although the precise pathogenesis of psychotic disorders has remained elusive, the past two decades have seen impressive advances in the field, thanks to the emergence of sophisticated technologies such as neuroimaging. Several neurobiological alterations in brain structure, physiology and neurochemistry have been documented that reflect diverse pathology (Keshaven, Tandon. Boutros & Nasrallah, 2008). It is highly likely that the development of emergent psychotic illness is the result of a biological alteration in neurobiological brain functioning and is not caused by personal weakness or family dysfunction. Families therefore, are not to blame for the emergent mental illness of their young adult child (as previously understood by a large sector of society).

The second assumption is that no parent ever expects to hear the words 'psychotic illness' uttered in reference to their own beloved son or daughter. The unsettling moment when a parent comes to realize that something is not quite right mentally, with their son or daughter has been described as a stressor of significant magnitude and one that causes ongoing worry and anxiety for parents (Molewyk &Doornbos, 2001; Czuchta & McCay, 2001). Moreover, the onset of a psychotic illness, like schizophrenia, bipolar affective disorder or major depression, in one's offspring is universally unanticipated and unwelcome. Parents are generally unprepared and perplexed when confronted with the unforeseen onset of mental illness in their beloved child. With few exceptions, in my professional experience, the onset of psychosis in one's adult child is a time of significant stress and distress. Parents find themselves in uncharted territory and suddenly immersed in an unfamiliar and unanticipated role, i.e., that of caregiver who does not always know how best to cope.

Thirdly, I approach this endeavour from a multitude of lived experiences that have shaped my assumptions and approach to this research. As an experienced clinical nurse specialist with a sub-specialty in providing family education and support within the context of an early psychosis team, I have worked exclusively with the parents of youth and young adults experiencing early psychosis during the last twenty years of my career. Within this timeframe, I have seen hopeful early psychosis intervention approaches begin to transform mental health clinician attitudes leading to the creation of several excellent models for recovery-based programs. Through my professional experiences within local and global early psychosis initiatives, and a careful accounting of the relevant literature (further elucidated in Chapter Two), I am convinced that the development of a psychotic illness is no longer a life sentence of chronic illness, or a downward spiral to a substandard life of social marginalization. The current availability of hope-filled treatments combined with timely family support considerably enhances recovery outcomes. While not everyone may experience robust recovery, the hope of recovery remains a strong possibility. Unlike when Patricia Deegan (1996) was labeled with schizophrenia, when owing to her diagnosis of chronic schizophrenia her life was essentially considered presumptively as ruined, young adults experiencing early psychosis today have the option of hopeful humane intervention environments that provide opportunities for recovery and empowerment.

Definitions of Key Terminology Used in this Study

Within any study there must be attention to language. In an interpretive phenomenological study language is especially important. Drawing on the writings of Gadamer (1976) in *Philosophical Hermeneutics,* "language is the being of everything which can be understood" (p.31). Although our understanding of spoken or written language may change according to the historical situation in which we find ourselves. This is important in relation to this study as the present social and historical context is one that consistently uses short forms, abbreviations and acronyms to communicate in verbal speech and written word. This is no less true of the early psychosis field where short forms, universal symbols and abbreviations surround us at every turn. I have used standard acronyms and forms intermittently throughout this document. My use of these shortened forms of language is not meant to reduce the human face of caregiving parents or to turn their experiences into less dimensional textual meanings. Rather, the short forms are employed to aid the reader. I have made deliberate efforts to write to be understood and to reduce the time it takes to read monotonous repetition of terms and to instead focus upon the occurrences of the phenomenon of interest.

The following acronyms and short forms will be used throughout the chapters of this document. A glossary terms is also available within Appendix A and will provide easy reference to these and other definitions or explanations.

EPI: Early Psychosis Intervention is the term used to describe an intervention setting, which espouses and adheres to the clinical framework for best practices as articulated by the Ontario Working Group Framework

FEP: First episode psychosis is the first time psychotic symptoms emerge.

Parent Caregivers: Any individual who self identifies as assuming a parental role with a young adult with first episode psychosis.

Young Adult: For simplicity, the term young adult will be used to describe all young people in their late teens and early twenties eligible for assessment and treatment for first episode psychosis. This includes all those between the ages of 16 and 30 years old.

Story: Human beings by nature lead storied lives and share stories of their lives. The real life experience of parent caregiving for a young adult with first episode psychosis is one such story. Thus, their 'story' is not a frivolous fictional fairytale account. Nor does it need to be validated by some outside source. Through my conversations with parent caregivers' they were given the opportunity to tell, retell and relive their experiences with their son or daughter's first episode of psychosis. Story constitutes the raw data generated in conversation with parent caregivers.

Some additional comments on language use and writing style

I have been deliberate in choosing to write this dissertation in a way that will be accessible to the parent caregivers who participated in this research. I wish to honour their commitment to this project and the experiences that they shared with me. Although I am confident that this inquiry will be useful to those comprising the academic community, my overriding aim is to speak plainly and with respectful appreciation to the people who provided me with the gift of their personal stories. I hope that I have been able to describe their experience and to interpret it in plain, but unpretentious language, allowing all readers to develop genuine closeness and feelings of resonance with the findings. It would especially please me if the results of this study find their way beyond academia and be embraced by mainstream popular literature, or even better, form the foundation of esthetic representations like poetry, art, dance or song. Only then will I have achieved my own goals. I am aware that the language of Heidegger is in itself a barrier to comprehension. As such, I have attempted to make the Heideggerian philosophy and concepts, accessible to all potential readers. Towards this end, whenever I use a Heideggerian concept in this document I deliberately place it in *italics* and where appropriate provide a brief description or definition of it (which is repeated in the glossary). My desire is to keep this document as free from the barriers of abstract and obtuse language as possible. I am writing for the parent caregivers and to engage others in understanding their experience of *being-in-the-world.* More about *being-in-the-world* and Heidegger's philosophy will be described in Chapter Three. Parents' longer quotes will be indented, italicized and double-spaced throughout this document. This will visually highlight their words. When parents' quotes are very brief they will be identified as italicized quotes within the text. Pauses and emphases will be highlighted in the following manner:

Transcription	Legend
…	Pause
[..5s..}	Longer pause [5 seconds]
[laughs] [crying]	Indicates a notable non-verbal feature
He was <u>angry</u>	Voice emphasis

In Chapter Two, I review the historical context of family caregiving of the mentally ill in the province of Ontario and then review other relevant background literature related to first episode psychosis, and early psychosis intervention. The inclusion of the historical context is quite deliberate. As present understanding is shaped by the past, I want to specifically highlight the situatedness and historicity of the current parental caregiving experience with reference to history. I also describe the challenges faced and the transformational possibilities experienced by the families of those young adults with emergent psychotic illness. Chapter three will articulate the tenets of phenomenology as underpinned by Heideggerian philosophy. Chapter four focuses upon the methodology as it was applied. Chapters five, six, seven and eight capture the synthesis of findings and provide the interpretive stories. Chapters nine and ten are the concluding chapters and provide both a reflective summary of the intepetive process as well as identifying next steps and potential aplication of the interretive synthesis.

CHAPTER TWO

We are not makers of history. We are made by history.
Martin Luther King Jr.

Exploring the Literature

Uncovering what we already know

My study focuses upon the experience of the parent caregivers of young adult children with emergent first episode psychosis. In this chapter, I first describe the historical context of family caregiving for those with mental illness from an Ontario, Canada perspective. I then provide a brief summary of the relevant literature regarding first episode psychosis (FEP), and early psychosis intervention (EPI). Next, I describe the salient issues with respect to family caregiver burden, and then review what is currently known about strengths-based and resilience-focused research on family caregiving. This chapter concludes with summarizing statements that serve to affirm and support the focus of my research study and to specifically identify gaps in knowledge and where nursing practice knowledge and healthcare policy can be enhanced.

Historical Context of Treating Mental Illness in Ontario and the Impact Upon Family Caregivers

History provides insights about what happened in the past, in the hopes that these notions can shape and inform future thinking and acting. Awareness of historical events is very useful both in clarifying the patterns of the past as well as highlighting contemporary issues. History also provides access to a more complete perspective of the situated context of this study. Historically, family relationships within the psychiatric system of care in the province of Ontario have not been positive. The way families were treated over the past two centuries has a vital bearing on the present dilemmas experienced by individuals and their families who currently seek treatment. Important insights for current mental health professionals are gleaned from an historical accounting of the dismissive and often mistrusting attitude towards families. Treating mental illness has long been a process of trial and error guided by prevailing public attitudes and the dominant medical theory of the time. Historically, shifts within these attitudinal and theoretical domains have resulted in mental health professionals embracing alternate treatment approaches. Notions of successful treatment have consequently resulted in changes and expectations of the role of family. In the last century in Ontario, families have gone from being the only caregivers for a relative with mental illness, to bringing their loved one for institutional care in asylums where families were encouraged to deliver their ill loved ones to institutions for what was called moral care. More recently during the phase of deinstitutionalization, families witnessed a reversal from the former custodial inpatient care, where large numbers of loved ones with mental illness were discharged from institutions with inadequate community supports to sustain successful community re-entry.

Longstanding Stigma

To Ontario settlers in the 1800s, mental illness held a stigma of demon possession that engendered significant fear in others (Porter, 2002). The dominate ideology of the time, deemed mental illness as a punitive consequence of being distant from God. In reality, conceptions about mental illness were so highly stigmatizing that families tried to hide the fact that a member was mentally ill. In well-meaning attempts to protect their loved ones from such stigma and resultant fearful alienation in the community, some relatives resorted to atrocious alternatives, such as locking their ill relative in cellars or attics or placing them in chains (Bell, 1980). As early settlers, it would have been an inconceivable hardship to have an unproductive and economically dependent mentally ill member living within the household, especially as survival in an inhospitable land was at stake (Porter, 2002). Certainly, insanity in early nineteenth century Ontario bore an especially negative stigma and its sufferers were very often deemed outcasts. A substandard life was not uncommon with imprisonment in correctional institutions (Smith, 1986). Within these jails, the mentally ill inmates received no specialized treatment and were simply locked up in damp cells or chained (Bell, 1980). Is it any wonder that families may have chosen to lock up an ill relative at home rather risk their love one being imprisoned indefinitely? Perhaps it may seem easy to judge these families, at least from the current 21st century treatment perspective, but early residents of Ontario had few, if any other, viable alternatives. These new Canadian settlers also brought with them notions of Bedlam and the inhumane treatment of those with mental illness.

The Dawn of the Asylums

Specialized care of the insane did not become a reality in Ontario until the early 1840s, when the legislative assembly passed a resolution authorizing a grant for the erection of a lunatic asylum (Brown, 1984). After years of pressure, political inertia, and political fighting in Ontario, an "*Act to Authorize the Erection of an Asylum within the Province for the Reception of the Lunatics and Insane*" was passed in 1839 (Brown, 1984). This act attended to tightening up the criteria and the process whereby an individual could be declared insane. This was appropriate given the previous history of incarcerating those who were simply poor but not at all unwell. This newly legislated process ensured that three practicing physicians were in agreement with a judgment of insanity. This was a particularly interesting function of the twofold act. This act attempted to prevent erroneous judgments of insanity, (which prior to this time were commonplace), and to protect the civil liberties of individuals. It also put in place safeguards that prevented families from "unloading unwanted or socially redundant relatives upon the government financed institutions" (Burgess, 1898, p16). An annual report written in 1878 by medical superintendent, Dr. Bucke, notes "that it is not the role of the province to care for those who are the responsibility of their family" (Bucke, 1887 as cited in Smith, 1986, p. 26). Herein, lays a very negatively charged assumption about families' responsibility, which may at least in part be at the root of a longstanding uneasy alliance between families and mental health professionals.

From the earliest days of asylum care in the province of Ontario, there appears to have been a mistrust of families' motives to escape their responsibilities towards an ill member. Even in 1878 the government seemed interested in saving money. It is interesting to note that this distrust has become systematized in several subsequent provincial committal policies over two centuries (Wright, Moran & Gouglas, as cited in Wright and Porter, 2003). Some families under duress and in the absence of suitable alternatives, no doubt abandoned their ill relatives to asylums, but others clearly attempted to maintain regular contact and still others paid for this care at a sum of $2.70 per week. Asylum records show numerous notations of family payment and family visitors (Smith, 1986). However, as Ontario became more industrialized and urbanized, fewer families were able to assume the burden of an unproductive mentally ill relative (Krasnick, 1989). This burden, coupled with the potential promise of a cure, led to a large increase in the numbers of individuals being admitted to the newly constructed provincial asylums just prior to the turn of the 21st century.

Moral Treatment

Moral treatment was a highly lauded approach, first tried by a Quaker philanthropist, William Tuke, at the York Retreat in England (Boling, 2003). His ideas closely followed those of Pinel and Pussin, who working in the Bicetre Asylum in France affirmed a non-restraint approach to care (Shorter, 1997). Restraint was considered to cause rather than prevent mental disturbance and was used only in extreme circumstances. A large number of Ontario asylums were built with the express hope of curing the mentally ill through humane and caring approaches. Four such asylums were built in southern Ontario. The first and largest was built in Toronto (1850), a second in Mimico (1861), another in Hamilton (1875) and another particularly large one in London, Ontario (1870) (Porter & Wright, 2003). All shared the notions of moral treatment. Common throughout this phase in Ontario asylum history, although in retrospect unfounded, was an optimistic premise that asylum care would bring a cure to those with mental illness and be a more effective place of healing than at home with family. Underlying this assumption was a notion of removing the ill person from the potentially noxious impact of their family members (Porter & Wright, 2003). The notion of moral care assigned a new family hierarchy with the superintendent at the head and the matron or head nurse as a pseudo mother figure. Again the widespread acceptance of moral treatment sent a clear message that families could not or would not provide what the ill person needed.

Dr. Joseph Workman was the medical superintendent of the Toronto Asylum and has been considered the *Father of Canadian Psychiatry* (Johnston, 2000). He embraced the tenets of moral treatment and was an advocate for humane care. Asylum advocates and supporters suggested that 90% of those treated for insanity would be cured and returned home to their families (Johnston, 2000). This expectation of almost certain cure arose from several positive reports from asylums in England and in the United States. Not surprisingly, the new zeal for being able to cure those with mental illness, led to Ontario families being more willing to admit their loved ones to asylums. The government opened the Toronto, London and Mimico asylums, for example, with great enthusiasm for the curative factors of moral care (Krasnick, 1981). However, there were no miracle cures in Ontario. Even though the southern Ontario asylums offered "moral treatment in which kindness, good food, fresh air and exercise were combined with a well ordered and pleasant physical environment and a supportive structured social community", the number of people who were actually "cured" was very low, estimated to be well below fifty percent (Johnston, 2000, p. 48). Below in Figure 1.1, is a picture of one of the large provincial asylums built in the countryside by the lakefront in Mimico, just west of Toronto, Ontario.

Figure 1.1 Mimico Asylum

However the success of these large asylums was not in their ability to transform lives, but only in providing custodial care for large numbers of patients in what quickly became overcrowded and substandard conditions (Reame, 2000). For families who had relinquished their loved ones to the promise of curative asylum treatment, there was no reversal. Once ensconced as patients in these large institutions, it was difficult, if not impossible, to ever return home. Each asylum collected a large cohort of patients deemed to be incurable. As the number of incurables grew, so did the overcrowding of the institutions. It was not uncommon, for example, to be admitted to one asylum and due to overcrowding, to be transferred to an alternative asylum facility in another (perhaps further away) geographical region (Smith, 1986). Sadly this process of transferring "incurables" had a very detrimental effect upon family unity and created a situation where the mentally ill were essentially estranged from loved ones. They were separated geographically from family and therefore unable to visit (Reame, 2000). For some, family relationships were maintained only through letter writing.

Engendering Mistrust

Historically, the failure of the asylum system to successfully make good on the promise of cure, likely contributes to families engendering feelings of distrust for the psychiatric care system. Although institutional care may have afforded a welcomed respite from providing care at home, the decision to put a loved one away, must have been very distressing. Families had to bear the heartbreaking guilt and pain alone of their decision. Indeed the stigma of mental illness was so severe that families held the illness of a loved one as a tightly guarded secret. Additionally, acting as yet another burden for families was the knowledge that care was not nearly as humane as had been promised (Krasnick, 1981). The hopeful pledge of new asylums was later replaced by the realities of increasingly overcrowded institutions often described as 'snake-pits' (Hatfield & Lefly, 1987; 2000, Maurin & Barnmann Boyd). From the perspective of loving families who held hopes for cure, the false promises of moral treatment was perhaps nothing more than a very disappointing and large-scale provincial psychiatric experiment.

The Dawn of Deinstitutionalization

Later in the mid 20th century, the government felt deinstitutionalization was more appropriate and certainly thought to be more humane. Deinstitutionalization is a long-term trend wherein fewer people resided as patients in mental hospitals and fewer mental health treatments were delivered in public hospitals. In Ontario**,** this trend saw the long process of gradually closing the large provincial psychiatric hospitals (former asylums) and transferring patients to community-based mental health services. After more than one hundred years of hospital-based care in Ontario, there was a sudden reversal in the philosophical conviction regarding the appropriate location of care. Three factors appear to be at the root of this reversal: 1) effective pharmacological treatments developed in the 1950's had a dramatic impact on the treatment of the most seriously ill psychotic patients; 2) a philosophy of 'least restrictive' care was a foundational principle in preserving an individual's civil rights; and 3) a perceived opportunity by government to reduce spending on mental health institutions. With the passing of the Ontario Mental Health Act in 1968, and more stringent committal criteria, it was even harder to hospitalize individuals against their will (Wright, Moran, & Gouglas, 2003). In any case, the inhumane era of warehousing the mentally ill 'out of sight and mind' in substandard provincial hospitals, simply had to come to an end. The plan as first conceived, was to provide a well-coordinated and comprehensive system of community care.

Unfortunately, the early optimism for deinstitutionalization was short-lived. The Ontario government did not provide adequate financial funding for this undertaking (Boling, 2003). Moreover, the development of an appropriate system of community care in Ontario has been slow to develop. The result has been a drop in bed capacity in mental hospitals but a concomitant recognition that discharged patients were living impoverished lives in the community, swelling the ranks of the homeless and, just as in the pre-asylum days, filling the jails (Goering, Wasylenki & Durbin, 2000). Not surprisingly, mentally ill individuals who were rapidly discharged into the community did not have the necessary life skills to cope on their own. Approximately 63% of these former patients returned to the care of their families of origin (Goering & Lin, 1996). This is an example of families paying the price of dismally inadequate planning on behalf of the provincial mental health care system.

The failure of deinstitutionalization remains a matter of considerable concern and has remained a high priority focus for provincial advocacy efforts from several family based organizations like the Schizophrenia Society of Ontario, (formerly called the Friends of Schizophrenics), which was developed in 1979. The advocacy efforts by family members or healthcare consumers or survivors, as they have come to call themselves, have been somewhat successful in shaping mental health policy in Ontario, specifically in matters of community based supports, provision for substitute decision-making and more family friendly committal criteria. However, despite these recent family advocacy efforts to enhance community supports, this aspect of the treatment system remains woefully under-funded, consuming only about three percent of the Ontario provincial health budget. (Freeman, 1994).

Caesar (2007), an American family advocate speaking about deinstitutionalization notes, “we have consigned many persons to lives of quiet desperation, have destroyed the mental and emotional health of those who love and care for them, and destroyed families” (p. 318). It appears that the consequences of deinstitutionalization upon families, on both sides of the border, were not fully comprehended by professional caregivers or those responsible for creating and instituting government mental health policy. Deinstitutionalization seemingly exploited the good nature of loving families whose de-institutionalized, mentally ill family member returned to the care and support of their relatives.

Theories of Family Etiology

Any historical review of mental illness and its impact upon families would be remiss not to mention the impact of associated family theories of etiology of mental illness. A review of the history of mental illness, as it relates to families, indicates that the resources of society and the attention of mental health professionals have strongly focused upon determining the etiology of mental illness. This is an admirable goal. However the family as the source of mental pathology has been a consistent focus. Freud’s emphasis upon psychotherapy and the assumed implications of early childhood experiences did nothing to affirm and support the families of the mentally ill. With a Freudian focus upon environmentalism, within parenting in particular, parents were blamed for being the cause of mental illness (Shorter, 1997).

The family as a causal factor in mental illness was noted in 1948. Fromm-Reichmann published her theory of the schizophrenogenic mother (Fromm-Reichmann, 1948, as cited in Shorter, 1997). According to this theory, the origins of schizophrenia lay in the relationship between mother and infant. It suggested that the mother unconsciously rejected the child, was cold and distant. Unfortunately for the families of the mentally ill, and in particular mothers, these theoretical notions caught on quickly. Even though the theory eventually proved to be false, there was considerable interest in its premise. It spurred a number of interactional theories of causation spanning at least three decades. Another similar study suggested that there was a double-bind communication style between an ill person and his or her family (Bateson, Jackson, Haley & Weakland, 1956). The assumption was that growing up in a family where a child received conflicting messages caused mental distress that led to mental illness. This theory suggested that serious mental illness was the result of a learned pattern of family communication, rather than an illness of the mind. Again, despite any kind of systematic research these theories became the basis of family therapy.

Similarly, Wynne (1978) having observed fragmentation and blurred meanings in family interactions noted disordered communication as the core problem of families of the mentally ill. If one were to focus solely upon the family therapy literature of the 1950's, 1960's and 1970's, one might erroneously assume that families cause serious mental illness. Unfortunately, this notion of causation persisted for many years, resulting in families participating in non-effective systemic family therapies and feeling exceedingly guilty for having created a shameful weakness in their offspring (Torrey, 1983). Despite growing scientific evidence of genetic vulnerability, neurobiological brain changes in structure and function, including biochemical imbalance, mental health professionals failed to absolve the family of causal responsibility or to inform families about the biological nature of mental illness (Kreisman & Slavinski, 1982). This is perhaps the most glaring historical failure of mental health professionals to date: a failure that no doubt continues to shape the acceptance of professionally designed family-based interventions. The plethora of family self-help groups and family peer-facilitated courses is perhaps a defensive and rejecting response by and on behalf of families to having been woefully blamed for causing or at the very least, maintaining mental illness in a loved one (Hatfield & Lefly, 1987).

Having Come Full Circle

Sadly, what has been consistently overlooked in the care and treatment of the mentally ill in Ontario is the impact of a mentally ill relative upon their family. Indeed the role and responsibility of the family has often been at odds with the role enacted by government to maintain social order. More recently the governmental policy of deinstitutionalization has attended to notions of civil liberty but has failed to recognize the difficult burden of caregiving placed upon families. We are now in a period of history where those with mental illness live in the community or with their family. Just as in pre-asylum days, the stress of caregiving and its associated stressors has been placed again upon families. It is perhaps not surprising that family difficulties with caregiving (often called burden, which will be discussed in more detail later in this Chapter) have spawned an abundance of family support and advocacy groups in Ontario.

It is also important to note that the etiological beliefs about mental illness, once espoused by Christian clergy and more recently espoused by the inadequate research of family therapists and mental health professionals, have historically added to the family's anguish about mental illness. For more than three decades, one family trait after another has been brought forth and vigorously supported as the definitive ”cause” of mental illness. Overtime, these theories have lost their credibility but not before they have inflicted unnecessary guilt and blame upon families who sought help. It is clear that the inattention and lack of concern for families of the mentally ill, coupled with a system of care in Ontario which failed to provide adequate supports for those with mental illness, has left a legacy of family mistrust and the historical roots of continuing adversarial relationships. Although presently there are increased efforts to include family members as partners in the care, treatment, and recovery of their ill relative, the shift to value the lived experience and expertise of families has been very long in coming. Where they were once blamed for causing mental illness, families are now regarded as an asset, and invited to be equal partners in the treatment and recovery of their ill relative (Hamilton Wilson, Hobbs & Archie. 1999; Hamilton

Wilson, 2009). It behooves nurses, other mental health professionals and mental health policy advisors to be alert to the fact that changes in treatment philosophies, suggestions of best practices and shifts in prevailing public attitudes and negative media portrayals have a substantial impact upon families of the mentally ill. These situated contexts have a bearing on the meaning of the caregiving experience.

The Dawn of Early Psychosis Intervention

One important shift in treatment philosophy and approach has been the development of a growing body of research depicting advantages to treating emergent psychosis as soon as possible. This has produced new interest in the families of the mentally ill with respect to their critical role as a vehicle for early identification of that first episode of psychosis and early initiation of treatment. The family is also seen as an important support for recovery. I offer this next section of the chapter to help the reader come to understand what is meant by first episode psychosis (FEP) and early psychosis intervention (EPI).

Psychosis

Psychosis refers to a loss of contact with reality, in which people have trouble distinguishing between what is real and what is not. The appreciation of reality is impaired and the individual may suffer from symptoms such as delusions (false beliefs), hallucinations (altered perceptions), mood disturbance and bizarre behaviour. When these mental health changes occurs it is called a psychotic episode (Milliken, 2003). Psychosis is a feature of several major mental disorders, notably schizophrenia, schizoaffective disorder and bipolar disorder, although diagnosis tends to be transient in the initial stages (Keks, & Blashki, 2006). Psychosis usually first appears in a person's late teens or early twenties. Approximately three out of every 100 people will experience a psychotic episode in their lifetime (Milliken, 2003). It occurs in men and women across all cultures and socioeconomic groups.

First Episode Psychosis

First episode of psychosis (FEP) is simply defined as the first time a person experiences psychosis. A first episode of psychosis is often very frightening, confusing and distressing, particularly because it is an unfamiliar and novel experience. Unfortunately, there are also many negative stereotypes and misconceptions associated with psychosis that can further add to the ill person's distress. FEP may happen suddenly or develop over several months or even years. The effect on the ill person and their family can be immense. The sufferer may experience confusion, depression, become socially isolated, and at times, even devastated by the disruption to their life and goals (Kilkku, Munnuka & Lehtinen, 2003). Henry Jackson (2004), an Australian psychologist and his colleagues conducted a descriptive study using standardized measures of post-traumatic stress and found that many of the patients discharged from the FEP unit in Melbourne, Australia, suffered trauma, both from their disturbing symptoms and also from the treatment itself. The treatment of psychosis can be very distressing for young adults, especially when it includes seclusion, restraint use or involuntary commitment (Gorrell, Cornish, & Tennant, 2004). Most often the onset is during late adolescence or young adulthood and more often than not the young person is living with their parents (Malla, Norman, & Joober, 2005). Parents too, suffer distress, fear and confusion. Family members hold the physical and emotional burdens of care and are just as likely to be co-confronted with the stigma and guilt associated with mental illness (Czuchta & McCay, 2001; Addington, Coldham, Jones, Ko, & Addington, 2003).

During the past fifteen to twenty years there has been considerable interest in FEP, especially in detecting it earlier in the course of illness. There are often prolonged delays (estimated to be in excess of more than twelve months), in initiating treatment for psychotic disorders (Norman, Malla, Verdi, Hassel & Fazekas, 2004). By the time those experiencing psychosis eventually seek help, they often present to the emergency department of a hospital with a collection of difficult symptoms such as, aggressive behaviour, suicidal tendencies, and substance misuse, all too frequently becoming involuntary patients (Malla Norman & Joober, 2005). When most patients experience FEP, it is at a time when these young adults are forming peer networks and beginning the transition from family to independence (Mackrell & Lavender, 2004). Psychosis at this phase of life means that many sufferers leave school or delay career training and education because of their mental health difficulties (Harris, Brennan, Anderson, 2005). Psychosis then interrupts the process of transition to adult roles while simultaneously prolonging the stage of active parenting for their mothers and fathers (Addington et al, 2003). FEP has an enormous impact on individuals and families (Chong, Mythily &Verma, 20005; Barker, Lavender & Morant, 2001; Jeppeson, Petersen & Thorup, 2005).

Early Psychosis Intervention (EPI)

The early psychosis intervention movement has emerged as a significant focus of psychiatric research and clinical service reform across the world (Edwards & McGorry, 2005). The overall aims of early psychosis intervention include the early detection of psychotic symptoms, reducing the time before first treatment, timely commencement of effective phase specific treatments, reducing secondary morbidity and chronicity and enhancing the recovery of psychosocial functioning (Joseph & Birchwood, 2005). All these aims have been formalized in the *International Clinical Practice Guidelines for Early Psychosis* (IEPA, 2005*)*. This document was developed by 29 international experts in the field and is shaping mental health reform worldwide. The premise is simple: to intervene as early as possible after the onset of psychotic symptoms in order to maximize recovery for the ill person. Although there are some continuing debates about the advantages of early treatment, specifically questioning the merit in identifying psychotic illness early, and raising questions about the effectiveness of specialized early intervention (as opposed to standard care), there is general agreement that early specialized and intensive approaches to treating first episode psychosis are more effective. In the following sections of this chapter I highlight the current state of knowledge about what is known about early psychosis and its treatment.

Early detection: reducing the time before first treatment

Interest in early psychosis intervention (EPI) began more than twenty years ago and has now become part of the main stream of psychiatry and mental health treatment. The EPI movement was born out of some very important studies that were conducted at the University of Melbourne, Australia, by Dr. Patrick McGorry and a large team of clinical researchers. This group was unified in a shared concern that despite substantial knowledge of highly effective treatments, few individuals received timely care, and if they did receive care, it was often provided in a pessimistic manner. Mental health clinicians held little hope for the ill person's recovery, which translated into minimal or substandard treatments being offered (Edwards & McGorry, 2002). To counter this potential, McGorry and colleagues came together to develop the Early Psychosis Prevention and Intervention Clinic (now called EPPIC for short), one of the most comprehensive and innovative clinical programs devoted to those with emergent psychosis. The Australian EPPIC model has since become the gold standard for early psychosis treatment in the developed world. I had the privilege of visiting Dr. McGorry and colleagues at the EPPIC program in the autumn of 1996. This visit to Melbourne, which included several educational workshops, was inspiring. It affirmed my own beliefs that the outcome from an episode of psychosis could indeed have a favourable recovery outcome. I also came to understand that excellent early treatment for the ill young adult and appropriate and hopeful supports for parents led to a greater variety of recovery possibilities.

The pioneering work started in Australia, has been an important catalyst for renewed enthusiasm for recovery efforts and a greater emphasis on secondary prevention. Seemingly the key to supporting and enhancing the most favourable recovery outcomes is by identifying psychosis as early as possible. Intervening in a comprehensive way, soon after the onset of psychosis, is of significant importance. A Canadian study by Jean Addington and colleagues reported that individuals experiencing psychosis for the first time tried an average of 2.3 times to obtain help and it took on average almost two years to receive appropriate treatment (Addington, Van Mastrigt, Hutchinson, &Addington, 2002). There is also evidence that treatment delays lead to less robust recovery outcomes. The time period between the onset of psychosis and response with appropriate treatment is important because the longer this delay, known as the "duration of untreated psychosis" (abbreviated to DUP), the poorer the clinical outcomes (Birchwood, 2000; Addington, Van Mastrigt & Addington, 2003; Drake, Haley, & Akhtar, 2000; Harris, Henry, Harrington, 2005). Harris et al (2005) conducted a prospective study over a period of eight years following first episode psychosis and provided the most positive evidence of the correlation between delayed treatment and poorer functional outcomes. Delayed treatment can: have an impact upon an individual's psychological and social development; strain peer relationships; disrupt school achievement or vocational goals; increase substance misuse; increase rates of suicide and depression; and, of central importance to my study, lead to a loss of family and social supports (Birchwood & Iqbal, 1999; Edwards & McGorry, 2002). The economic and societal impact of untreated psychosis should also be considered since potential consequences include homelessness, incarceration and reduced prospects for long-term recovery (Birchwood, McGorry & Jackson 1997; Larsen, Melle & Auested, 2006).

Timely commencement of effective phase specific treatments

Treatments, specific to the needs of individuals experiencing early psychosis have been the focus of considerable research in the last ten years. Most of this research has taken place in streamed treatment delivery systems to engage and invite these youthful patients into treatment partnerships during the critical period for maximizing treatment effects (Birchwood, 2000; Hamilton Wilson & Hobbs, 1995). This critical period has been defined as the time between the initial emergence of psychosis and the three to five years that follow. The key here however, is not simply offering any treatment but mounting a comprehensive and intensive treatment effort. In essence it is not good enough to simply intervene early. There must also be an expectation to intervene well (Addington, 2007).

So what does intervening well look like? The answer to this question is difficult as there are a large number of treatment programs described in the literature and each appears to have its own variation on the theme of comprehensive, phase specific or recovery oriented treatment approaches. None the less, there is considerable agreement best EPI efforts lead to decreases in suicide rates, relapse rates and readmissions to hospital (Petersen, Nordentoft & Jeppesen, 2005; Craig, Garety & Power, 2004). Certainly, a significant advantage is the decrease in suicide rates and associated feelings of hopelessness. Additionally, there appear to be other advantages. The best evidence-to-date comes from the Australian EPPIC program. This phase specific approach to psychosis intervention has shown superior treatment outcomes for positive and negative symptoms, improved social functioning, lower levels of self-harm and aggression towards others and fewer hospitalizations (Power, Elkins, & Adlard, 1998; Carbone, Harrigan, McGorry, 1999; McGorry, 2005).

Canadian Research Initiatives

Similar early treatment research has been conducted in Canada. The Calgary Early Psychosis Program and the Prevention and the Early Psychosis Program in London, Ontario are noteworthy in their contribution to what we have come to know about phase-specific treatment approaches. Both are community-oriented programs offering a combination of medical and psychosocial treatments within a case management model. Outcomes measures from both these clinical settings, suggest significant improvement in psychotic symptoms and functional outcomes. Of special mention, these Canadian research teams also collected family data, which will be described a little later in this chapter (Payne, Malla, Norman, Windell, & Brown, 2006; Addington, Collins, McCleery, & Addington, 2005).

Reducing secondary morbidity from FEP and enhancing the recovery of psychosocial functioning

Currently there are effective treatments, albeit still not perfect, to reduce symptoms of psychosis and enhance recovery. The symptomatic recovery from an episode of psychosis is estimated to be 80-90% (Robinson, Woerner & Alvir, 1999). However, symptom recovery is not enough. Remission of psychotic symptoms through targeted medication strategies is often the easy approach to treatment, although it certainly requires an artful approach. There are many drug studies reported in the early psychosis literature which all suggest efficacy in ameliorating the positive symptoms of psychosis. A full review of the pharmacological studies will not be included here as the focus of this research is not upon treatment selection but upon the parents' experience of their young adult child developing psychotic illness. Nonetheless, anti-psychotic medications are considered a cornerstone in good intervention, but medication alone is insufficient to produce a robust remission of symptoms and enhance recovery outcomes (McCleery, Addington, & Addington, 2007).

The aim of reducing the disability associated with psychotic illness requires a more intensive phase specific and holistic approach. Nonetheless, the personal costs associated with the co-morbidities of poorly treated psychotic illness are considerable. These co-morbidities include: addiction, tobacco smoking, suicide, anxiety, and depression to name a few. Suicide risk is particularly high in the early stages of recovery but can be reduced by early treatment. (Power, Bell & Mills, 2003). Patients in specialized EPI treatments were noted to adhere more closely to their medication regimes, spent more time engaged in educational and/or vocational pursuits and were better able to re-establish social relationships following their acute illness episodes (Addington, 2007). The reduction in disability in the young adult with FEP has positive implications for their caregiving parents.

Addressing the needs of caregiving families

It should come as no surprise that families play an important role in recovery for young adults with emergent psychotic disorder. With the movement away from hospitalization in favour of recovery-oriented community-based care, families are increasingly involved in the lives of their ill relatives; a large number of parents are the primary caregivers (Hamilton Wilson, Hobbs, & Archie, 1999). The first exposure to psychotic symptoms is difficult for families to comprehend. In fact, families tend to report the greatest amount of distress in the years immediately following the onset of psychotic illness (McCann, Lubman, Lu, Crisp, Leggatt, Clark, 2007). Family members often experience high levels of psychiatric distress in the form of anxiety and depression. Family caregiver burden is also a consistent concern. Consequently, targeted comprehensive and phase specific early psychosis treatment programs that include appropriate and readily accessible family supports have been well received (Hamilton Wilson, Hobbs & Archie, 1999; 2005). However, just what have we come to know about the lived experience of family caregivers in response to the emergent psychotic illness of a young relative? Is it possible to identify supports and approaches, which if employed at early stages of illness, will support family needs and contribute to overall family health and resilience?

Caregiver Burden

The adverse consequences of caregiving known as caregiver burden for a family member with serious mental illness have been researched for more than five decades. A comprehensive review of all of this literature is well beyond the scope of this thesis; therefore I focus instead upon studies that serve to illuminate the issues faced by family caregivers during the emergence of psychotic illness in a loved one. Certainly, there can be no doubt that caring for a mentally ill loved one has an impact on family caregivers. Historically researchers have focused upon the negative aspects of caregiving felt across a broad spectrum of family life events including: work, leisure, income, children, family health, and relationships with extended family (Hatfield & Lefley, 1987). Hoenig & Hamilton (1966) differentiated two kinds of burden: objective and subjective burden. Objective burden has been defined as the measurable and observable adverse effect that a person with mental illness has on the household, such as troublesome behaviour and disruptions of family life. Subjective burden has been defined as the emotional impact of caregiving upon the family of which stigma and grief are two examples (Hoenig & Hamilton, 1966). These researchers observed that family members of an individual with severe mental illness had to put their own needs and desires on hold deferring to those of the ill relative. Other early studies confirmed that families caring for a mentally ill relative face a range of practical and emotional stresses (Brown, 1966; Grad & Sainsbury, 1968).

Unfortunately, there is a lack of consensus on the effect of the various factors considered to be associated with the experience of family burden. Despite research being conducted over fifty years, there is still very little agreement on the variables that influence family burden. This lack of agreement is a function of differences in the definitions of family and of burden, the varied tools used for the measurement of burden and the time period being studied. In the absence of an agreed upon conceptual framework and consistent, theory-derived definitions and measurement tools, it is difficult to compare the results of family burden studies. When reading between the lines, most of the research literature shows an affirming reaction to the dominant notion that families played an etiological role in individuals developing mental illness. A number of researchers have attempted to demonstrate an association between the attitudes of family caregivers and the illness course of the ill family member (Brown, Birley, & Wing, 1972; Brown, 1966; Fadden, Bebbington, & Kuipers, 1987; Grad & Sainsbury, 1968; Hoenig & Hamilton, 1966; Lowyck et al., 2004). Research was seemingly motivated out of a belief that mental illness was caused or at the very least exacerbated by the family environment (Hatfield & Lefley, 1987). Nonetheless, there is consistency in the general finding that the experience of family distress or burden is associated with the severity of disruption caused by the ill relative (Cuijpers & Stam, 2000; Czuchta & McCay, 2001; Doornbos, 2001; Grad & Sainsbury, 1968; Hatfield & Lefley, 1987; Ip & Mackenzie, 1998; Lee, Strauss, Wittman, Jackson, & Carstens, 2001; Lowyck et al., 2004). The more acutely ill and disruptive the ill relative's behaviour, the more distress or burden family members experience. This finding is important as it has a direct bearing on families of those with emergent psychosis, but also upon the recovery outcomes of those with psychotic illness (Tsang, Tam, Chan, & Chang, 2003).

With the current trend away from hospitalization in favour of less stigmatizing community-based care for those with emergent psychosis, the preferred location of treatment is now the family home. Parents, generally unprepared for this role are almost always the designated caregivers during very acute phases of early illness. The nature of emerging psychosis, including symptoms which impact upon the rational thoughts, feelings and behaviours of the ill relative, can most profoundly disrupt the day-to-day lives of the family. This brings to light an erroneous assumption in current EPI policy that the family caregiver role is somehow benign and will not put undue burden on a family, but this is far from the reality described by families (FMHA, 2006; Kirby & Keon, 2006).

Most research has been conducted with family members of those with serious and persistent mentally illness, which point to issues of significant family burden. However, in these scholarly works, the family often comprises simply one individual family respondent on behalf of an entire family. This does not really constitute family research, but rather research on individual members of a family. For example, Chafetz and Barnes (1989) conducted focused interviews with individual members of twenty different families to ascertain the impact of caregiving upon family members. This qualitative study found that the problems experienced by families were related to protracted parenting and poor quality supports available. Tessler and Gamache (2000) attempted to define the care and control dimensions of burden. Care dimensions included helping with money, medication adherence, or transportation. They also described individual family member's efforts to control socially difficult behaviours exhibited by the ill relative, i.e., embarrassing behaviours, nighttime disruptions, suicidal gestures or aggressive behaviours.

Is caregiver burden present immediately?

Varying definitions of the concept of burden make it difficult to compare research findings. Additionally there are very few studies that specifically address the burdens experienced at the onset stage of illness. Most of the burden studies to date have been conducted with families of those individuals with long standing severe and persistent mental illness who have developed a significant degree of disability. It is difficult to know if the process of caregiving is the same for those with emergent psychosis as it has been described for those with chronic and persistent illness. Hopefully the situation of family members with relatives at an early stage of illness may in time illuminate different patterns in responses to psychiatric care.

Mors, Sorenson & Therildsen's (1992) prospective study of 73 caregiving relatives found that when individuals experienced acute illness symptoms for more than one year, families were more distressed and had higher scores on measures of subjective burden. Additionally, when compared to families of those with subsequent relapse episodes, they were initially quite optimistic about the services offered to them by the hospital personnel. This finding is important in two ways. Firstly, many families described being distressed both before and after an admission to hospital; the longer an ill relative experienced distressing symptoms, the more subjective burden was experienced by families. This result also points out that the distress experienced by families of youth experiencing emergent psychosis is not necessarily of short or transient duration. Also of interest is the finding that the family members of those with first admissions were much less critical of the care and services provided to them than families whose relatives were experiencing subsequent episodes of recurrent illness. Mors et al. (1992) concluded that this first admission group of relatives still held great hope for the recovery of their loved one and expected great things from the psychiatric service system.

Jean Addington and her team (2003) also conducted a study with only families of those with first episode psychosis and found that the early impact of mental illness had an impact upon family life. Again they found that increased levels of family distress were associated with a younger age of illness onset, and with the degree of functional impairment present in the ill relative. Family caregivers' appraisals of the impact and consequences of early psychosis had the greatest impact on psychological wellbeing in family members. It must also be stated that in each of these studies there were families who, despite reporting high levels of stress, did not exhibit corresponding levels of caregiving distress. These families were seemingly resilient and more able to adapt to the emergent psychotic illness. So what accounts for this resiliency? What coping skills are significant for families?

Several studies of family caregivers of young adults with early stage psychosis have illuminated that families, despite experiencing ongoing burdens, maintain hope for their loved ones' recovery following initial contact with the system. (Addington et al., 2003; Addington, McCleery, & Addington, 2005; M. Birchwood, 2000; Birchwood et al., 1997; Ehmann, Gilbert, & Hanson, 2004; Gonzalez, 1997; Hamilton Wilson et al., 1999; Mors et al., 1992; Tennakoon et al., 2000). Additionally families at this early stage of caregiving perceive the psychiatric system as a viable option for assistance not just for the ill relative but also for support and education for themselves. Most of the families participated willingly in the studies, which included support or educational interventions. These studies also seemingly highlight a critical period for provision of optimal family supports, i.e., from the very first moments of emergent psychotic illness.

Supporting family needs to reduce burden

As early psychosis treatment programs are still at initial stages of development it is imperative that mental health service providers work to create services that strive to meet the needs of clients and families. A basic tenet of EPI is that when families are well supported, the recovery of the mentally ill relative is enhanced. To this end the Ontario Policy Framework stipulates that,

> Education is available in a timely way to support all families of individuals experiencing their first episode of psychosis and that support to families is tailored to meet their changing needs (OWG, 2004).

This is an important objective that aims to reduce family distress and burden as well as maximize the recovery of the ill relative. But how specifically do EPI program approaches meet the needs of all members of the family? Just what are the needs of the families of those with emergent psychosis? What does the literature say about family needs?

EPI family needs

Unfortunately, very few studies are available which specifically identify the needs for EPI family caregivers. However, we do know that a care system which focuses upon the recovery of persons with mental illness must also support the family context in which that recovery takes place (Jones, 2005). Given that families historically and presently shoulder most of the burden, it is natural to assume that families need to be active participants in the care system. The three important messages from the burden literature can be summarized as follows: 1) proper support for families are important to the recovery process of the ill relative; 2) families that are not adequately supported are at greater risk for significant burden and health problems themselves; and 3) not all families are burdened by the experience of a young adult's emergent psychosis. Some families are actually resilient. Given the right tools and information, families can and do make a significant contribution to recovery (Abelenda & Helfrich, 2003). Perhaps if families are supported from the initial moments they enter the care system with a psychotically ill relative they may experience significantly less burden and distress. According to the family comments included in the Kirby-Keon Report (2006), families have historically had inadequate input into the design and delivery of mental health services. EPI initiatives must meet the challenge to enhance family participation in both the design and delivery of services. This is required for a couple of reasons: for the fullest recovery of the ill relative and the least burdensome impact upon the family (Jones, 2005).

Encouraging hope-filled futures

Research evidence from EPI intervention studies gives families new hope for their relative's recovery. However families need to know as much as they can about the nature of psychosis, including all the possible treatments and identify ways that they can help. Numerous examples of psycho-educational interventions have been described in the literature. Although most are intervention studies which focus upon family communication skills which reduce psychotic relapse in individuals with serious and persistent illness, the findings are applicable to early intervention families (Pekkala & Merinder, 2005). The evidence for the efficacy of family intervention in reducing relapse has been so well established it is now considered an evidence-based treatment (OWG, 2004). EPI families need to be educated in a timely way and as part of an ongoing process relevant to their specific situation. Despite this agreement in principle such family treatments or supports are not routinely available in Ontario (OWG, 2006).

Addington and Gleeson (2003) identified five goals for first episode psychosis family work to: 1) maximize adaptive functioning of the family; 2) minimize the disruption to family life; 3) minimize the risk of grief, stress and burden experienced by families; 4) assist the family in understanding the impact of psychosis on the family system and individual members; and 5) clarify the interaction between the family and the course of psychotic illness. These five goals were shaped by early family research conducted with families in Australia and the UK (Birchwood et al., 1997; Cuijpers & Stam, 2000; Fadden, 1998; McGorry et al., 1996). Of course, the goal that is most applicable to this literature review is the third one: to minimize the risk of grief, stress and burden experienced by families.

Given that the reformed Ontario EPI care system is still quite new having been available only since 2005, there is only a small number of individuals who have experienced the new specialized services. First episode psychosis is a novel and unanticipated experience for all members of the family. Most often none of the family members will have any former experience with psychosis or with the psychiatric care system. This is one of the unique features of this early psychosis family population. They are coping with a novel family stress for which they have no prior experience and are at a stage where the acute episode is likely mystifying and frightening. They don't know what to expect of the care system much less know how best to be successful in navigating the maze of available options.

In the near future, there should be more data available which will add to our understanding of the needs of early psychosis families as the EPI policy framework, sensibly included aspects of consumer/family evaluation. Until that time, program architects are resigned to using retrospective data from families of those who have traveled the system before. Obviously this approach has significant limitations as it provides more information about what not to do, rather than providing quality evidence about how to best meet the needs of families at early stages of caregiving. Nonetheless, if the goal is to minimize the risk of prolonged grief, perceived stress and caregiver burden experienced by families, then reflecting upon the data from families who have previously experienced these stresses can aid in the determination of variables deemed most frustrating or problematic to families.

Retrospective family surveys

To date a few retrospective survey studies of this nature have been completed. One of the best known was conducted by Hatfield and Lefley (1987) who surveyed families attending self-help groups. Families were asked what kinds of things they felt were helpful in coping with the mental illness of a loved one. Surprisingly these families sought help from friends and families first and then reluctantly from professionals. Perceived value of help from friends and family significantly outweighed professional assistance. Hatfield's survey generated a list of helpful interventions that families felt they needed: assistance in understanding the ill relative's symptoms; specific suggestions for caregiver coping; opportunity to relate to persons with similar experiences; substitute or respite care; and affordable housing options for the ill relative.

Holden and Lewine (1982) also surveyed families to ascertain their evaluations of mental health professionals. Generally the families surveyed suggested that their involvement with professionals left them feeling guilty and defensive. They described a tendency for professionals to be vague and evasive when pressed for specific answers. Additionally families suggested that they were not provided with sufficient information or coaching to successfully manage. Families wanted clear advice and suggestions that would help them manage the behaviours of their ill relative. Professional attitudes and behaviours then may inhibit the non-hierarchical collaboration deemed essential to establishing a working partnership with families.

As collaboration with family partners is a mandate of Ontario EIP policy, there appears to be a need for professionals to rethink attitudes towards families (OWG, 2004; Hamilton Wilson, 2009). Clearly the success of new efforts to work collaboratively with families will depend upon the degree to which professionals are sincere in wanting to really understand the family from a family strengths perspective. For decades, professionals have studied one family trait after another, which is then hypothesized as impacting upon the health and relapse rate of ill relatives. This focus has led to assumptions of family pathology and resulted in little concrete assistance to improve the experience of family caregivers. This has led some to suggest that the concept of family burden is a condition resulting from an unresponsive mental health service delivery system in dire need of change (Hatfield & Lefley, 1987).

Ontario models of EP family intervention

There are three examples of family support within early psychosis intervention already in operation in Ontario: in Toronto (Addington, McCleery et al., 2005), in Hamilton, (Hamilton Wilson et al., 1999) and a third in London (PEPP, 1999). Others are just beyond the formation stages in Peterborough, Ottawa, Kingston, Thunder Bay, Kitchener Waterloo and Windsor (OWG, 2006). All are required to subscribe to the goals of family intervention articulated in the Ontario EPI policy statement; however, only the one in Toronto has engaged in family studies to date. Although several quantitative prospective studies are in process, the results are not yet available. However the evaluation measures selected to date tend to be focused upon families as the context of individual recovery and not upon the fuller experience of what it means to have a member with emergent mental illness (Trainor, 2006).

Findings reported from the Toronto based study affirms the importance of clinical efforts to be responsive to family needs in a proactive way and to be focused upon the needs of all family members and not just upon efforts which enhance recovery or reduce relapse in the ill relative (Addington, Collins, McCleery, & Addington, 2005). This staged-model follow-up study did find a decreased level of family burden in response to enhanced supports and educational resources available to families. It used a stage-model of recovery-based family intervention that highlighted an individualized approach to a wide range of family interventions in addition to a number of interdependent treatment modules for the ill relative. It is a model that shows considerable merit and appears to empower caregivers by overtly recognizing their strengths, and aspires to view families as important collaborators. The family supports and interventions are part of a recovery oriented treatment system. Other new early intervention programs need to continue to evaluate their interventions. More qualitative studies will also help to enhance our understanding of the meaning of the early psychosis experience of parent caregivers.

From family burden to family resilience

Research of family burden has made an important contribution to understanding the family perspective of mental illness, but it has unfortunately only focused upon the negative aspects of caring for a mentally ill loved one. Such research has had the effect of erroneously describing families as passive receptors of burden disabled by issues of stigma, shame and blame (Schulze & Rossler, 2005). To date, very few studies have attempted to elicit the meaning that caregivers derive from the caregiving experience, nor have they described positive aspects of caregiving. Could there be protective factors operating in a family which protect them from experiencing caregiver burden? Why does one family succeed in the face of extreme burden while another fails with practically no distressing burden experience? Perhaps, the term burden ignores the positive aspects of caregiving that may be operating in a family. Phrased differently, early psychotic illness puts families to the test and compels them to ascertain whether their coping strategies are sufficient to deal with the situation.

A few studies found that the experience of caregiving can be transformative. Bulger et al. (1993) studied a group of 60 caregivers who attended a self-help group and found that family respondents frequently reported caregiver gratification and a sense of intimacy with their ill member. None of the family members reported a complete absence of gratification. In fact, when given the opportunity, this group of families described more gratifications than burdens. One hypothesis is that these families had benefited from the support of the self-help group, which had helped to reduce their social isolation and their sense of perceived burden. However, another interesting finding emerged from this study. Caregivers who were more disadvantaged by lower income, education, minority status and formal supports were happier with their caregiving roles than those who were more advantaged. Additional study is required to understand this interesting finding more fully.

Another study conducted by Yamashita (1998) sampled twelve Canadian and fourteen Japanese families who had a relative diagnosed with schizophrenia. Using Newman's (1994) nursing theory as the conceptual framework, Yamashita conducted serial interviews with families. This research reported that families, although definitely having experienced long periods of struggle, did eventually reach a turning point where they could transcend their perceived limitations. One such transformation was commonly the result of self-directed educational efforts that assisted family members in understanding more about their relative's illness. Being able to make a distinction between the illness and the symptoms of their relative, who was not to be blamed for the sickness, deepened the family sense of empathy for the ill relative.

Specific turning points for Canadian families were also uncovered, i.e.: accepting the illness; accepting the uncertainty of the illness; understanding behaviours as a result of illness; and feeling more accepting of their ill relative. Japanese families described different turning points, i.e., although they did not fully understand the illness, they did understand the evolving relationship with their relative prior to illness onset. When interviewing the same sample of families one year later, Yamashita found that all families, particularly the women in the Canadian cohort, had experienced turning points which led them to “getting on with their lives” (Yamashita, 1998 p. 517)   The majority of participants noted the reciprocity of the caregiving experience, more success in caregiving over time, and were overtly proud of the recovery efforts of their ill relative. This finding is in agreement with findings from two other burden studies that noted that burden scores tend to decrease overtime (Hatfield & Lefley, 1987; 2000). This suggests that families come to an adaptive stance and thereby experience less burden.

Family resilience

Walsh (2003) describes resilience as the ability to withstand and rebound from disruptive life challenges. Resilience has become a very new concept in mental health research. If a family is confronted by a crisis, like the emergent psychotic illness of a young member, family resilience becomes important. These are factors which are intended to help a family recover from a period of adversity (McCubbin & McCubbin, 1993). Family members of those with a first episode of psychosis have to deal with many emotions, and accordingly report less satisfaction with family functioning, and more difficulties with personal adaptation than the general population (Greeff, Vansteenwegen, & Mieke, 2006). Fadden et al. (1987) commented that “despite their burden, relatives do not complain much, although they receive little support, advice or information from the professionals engaged in treating the patient”. Is this a function of family resilience? Although some families are shattered by crisis or chronic stress others are strengthened and are more resourceful.

Seemingly, strengths and resources enable individuals and families to respond successfully to challenges, to recover and grow from these experiences. The concept of resilience affirms observations that some people and families, despite obstacles burdens, and struggles, cope very well. Walsh notes that a family resilience perspective recognizes strengths and potentials along with limitations, and recognizes the potential for personal and relational transformation and for growth forged out of adversity.

To date, there are very few published studies that affirm the strengths of family caregivers. As previously stated, an inordinate amount of research has been devoted to the study of family burden. Doornbois (1996) was one of the first researchers to study family stress , family coping and health in families of those with mental illness through comparing findings with normative families. Using a convenience sample of 85 families she conducted a mail survey. Doornbois found that the families of the mentally ill had substantial functional abilities i.e., the ability to do what it takes to preserve family integrity. Although the families of the mentally ill had more objective stressors than normative families, they also demonstrated effective use of specific problem-solving and behavioural strategies to enhance coping. Specifically these families used coping strategies of passive appraisal, seeking spiritual support, and using community resources.

The effective use of community supports and resources was similarly noted in a previously reported small study conducted by Chafetz and Barnes (1989). Norbeck et al. (1991) also found an association with social support and successful family coping. The overall adaptability of the families of the mentally ill in these studies indicates flexibility and adaptation in response to caregiver stress. The family cohort in the Norbeck et al. study confronted significant distress but were able to mobilize and change in accordance to the stresses they confronted. Looking at the process of caregiving through the lens of family resilience offers several advantages. By definition, it focuses upon strengths under situations of significant stress and does not assume that there is one singular way to achieve or maintain family health and functioning. Families are assessed in context, i.e., relative to each family's values, resources and challenges (Hawley & Dehaan, 1996; Walsh, 2003). Future study on how families maintain resilience holds great potential for improving efforts to prevent caregiver burden, especially for those confronting the early stages of psychotic illness.

Moving Forward from Here

Families, in particular parents take on significant caregiving responsibilities for their mentally ill loved ones. Unfortunately, given the novel nature of an emergent episode of psychosis, parents are generally unprepared for the many challenges inherent in this caregiving role. Few have the knowledge required to cope successfully with unusual behaviours, the treatment system or community resources. In the absence of empathic care systems that can guide family action plans, families may become frustrated; any negative internal or external appraisal of their situation leads to further distress or burden. Still, newer research findings suggest that there are several factors that can reduce family distress and enhance family coping. Information and education offered in a timely way on an individual basis at first, and then within group or self-help formats can significantly empower families (Addington, Collins et al., 2005). This is especially important in the new early psychosis initiatives within the province of Ontario that operate within a policy framework of recovery-based principles. Families need help to understand what is meant by recovery and specifically provided with clear information about how they can best serve the needs and recovery aspirations of their ill relative. When families learn the basics of recovery skills such as hope-instilling strategies, building on strengths, providing choices and avoiding learned helplessness, overall family recovery is more likely to be achieved (FMHA, 2006). There is an association between the severity of mental illness symptoms experienced by the ill relative, and the degree of distress experienced by the family. This finding points to the importance of efforts to help families cope with disturbing symptoms in practical problem-oriented ways.

Too often families express frustration with professionals' actions that are construed as evasive or defensive. As such, the notion of collaboration is crucial to enhancing success in caregiving. As nurses, we must always remain cognizant that the wellbeing of families is interconnected with the wellbeing of those with emergent psychotic disorder. Therefore, nurses working within EPI programs need to feel comfortable providing clear direct advice and not provoke an impression that they are prepared to watch families falter. When caregiving families are better understood by mental health providers and the family caregiving role is overtly affirmed and acknowledged, the understanding could facilitate the creation of better family support interventions. Moreover families constitute a critical piece of the complex network of individuals and organizations that make up the mental health care system. Therefore, the needs of family members must be a priority for early intervention initiatives. The role families play in the care of their ill loved ones is an important contribution to the health care system, and clearly justifies greater investment in family supports and services that enhance their resiliency.

Serving Family Caregivers Better

In this chapter, I summarized both the historical background and the current research context in which the parents of youth with emergent psychosis currently find themselves located. Clearly there has been a history of distrust between families and the care providers of the mental health system for a very long time. Families (mothers in particular) were once even perceived to be the causal factors in the genesis and maintenance of mental illness. Notions of moral care and the possibility of a cure led to large numbers of families bringing their ill relatives into the care of early asylums. But when the numbers of real cures were disappointing, the institutions soon experienced overcrowding. Former treatment aspirations transformed into simply warehousing the mentally ill in highly structured jail-like settings until the phase of deinstitutionalization in the early 1980’s. Families were helpless to make much of an impact on this large institutional system of provincial hospitals.

Mental illnesses were seen as chronically hopeless and it was not until the last three decades that recovery from serious mental illness was deemed possible. In fact the research into early intervention has provided a most consistently positive message about the possibilities of recovery. EPI research has also suggested the important role families can and do play in enhancing clinical outcomes for an ill relative. Families, once shunned as causal agents, are now embraced as partners within early intervention settings. Rather than being perceived as fragile and vulnerable to experiencing chronic caregiving burden, we now see families as capable of resilience and in possession of considerable strength. However, without an understanding grounded in the perceptions of caregiving parents, who have experienced the emergent psychotic illness of a young son or daughter, we do not have a starting point of reference for future studies focusing upon developing family interventions for EPI practice. In Chapter Three, I elaborate further about how my study unfolded.

CHAPTER THREE

The greater the science, the deeper the sense of mystery. Nabokov

Departing From Quantitative Research Roots: Embracing an Interpretive Paradigm

This chapter specifically explores my journey in coming to employ interpretive phenomenology as a way to understand the caregiving experience of parents in response to their young adult child's first episode with psychotic illness. After having come to the question: "How is first episode psychosis experienced by parent caregivers of young adults with emergent psychotic illness" I needed to select and commit to the appropriate qualitative methodology to answer this question. Following discussion regarding qualitative methods in general and affirming my own reasons for selecting to employ Heideggerian phenomenology, I summarize my understanding of the philosophy of Heidegger as it informs a way to understand human beings. The writings of many authors referenced within this chapter have all contributed to my understanding of the Heideggerian phenomenological view of person. However, Conroy (2001; 2003), Dreyfus (1989), Leonard (1994), and Munhall (1994; 1997; 2012) have had a more significant influence upon my understanding of Heidegger.

Following discussion of the Heideggerian philosophical aspects of relevance to a study of parent caregiving I provide a brief description of the

‘Pathways for Interpretive Research’ articulated by Conroy (2003) that served as a guidepost for my conversations and concurrent interpretive synthesis. Within Chapter Four, I describe the inquiry approach (Methodology) as I applied it to complete this study. I’d like to reiterate that words written within the text in *italics* are Heideggerian terms. The use of *italics* is to visually facilitate the identification of Heideggerian terms or concepts. The glossary of Heideggerian and other dissertation related concepts in Appendix A also serves as a quick reference tool for the reader.

Finding my way

As I approached this study I knew with some degree of certainty what I did not want to do. I did not want to use a quantitative approach, which reduced the experiences of parent caregivers to statistics. I also knew that I did not want to measure just some aspects of parents’ experiences, for example, their objective or subjective burden, their anxiety, their general health status or their perceived stress. I wanted to approach this study in a holistic way that would give voice to the meaning of parent’s experience as they encountered the first episode of psychosis in their young adult child. With some, now obvious naïveté, I thought that I would simply interview parents about their experiences, summarize these and report the salient themes I found within these transcribed conversations. I really thought this would be an easy process, and one that would inform subsequent nursing practice. I was well into the doctoral studies process and almost completed my course work before I came to understand that a qualitative study was not an easy process, and that to conduct a rigorous and trustworthy study would take much more time and effort than I had originally understood. Although I was still unclear about the actual processes or “how to” of qualitative research, I was not discouraged and remained quite interested in developing what I perceived to be new research skills. I also felt that my well developed interpersonal and interviewing abilities combined with my everyday relational ethics would help me to approach this research with respectful care and compassion.

Acknowledging my passion for the inquiry topic

The dawn of a grown child’s approaching adulthood and increased autonomy can rekindle and re-affirm long standing parental hopes for the loved offspring to reach their potential. I can vividly remember this anxiety-provoking period of parenting with my own two daughters, as one which left me feeling intermittently very proud of the capable young woman each had become, and at other times consumed with a nagging worry about their individual capacities to succeed as independent adults. My hopes for their health, happiness, self-esteem, social affiliation and enhanced autonomy were amplified at this launching stage of parenting. I also worried about their mental health. After all, not only was I a psychiatric nurse with nearly twenty years of clinical experience on a specialized psychosis team, I am married to a man with mental illness. I feared that the genetic predisposition would express itself in my children. I knew all too well, the risks of the onset of serious mental illness in early adulthood.

Moreover, in my clinical practice as Family Educator on an early psychosis intervention (EPI) team, I witnessed many parents as they came to understand that their son or daughter had developed first episode psychosis (FEP). This early journey of initial concern and awareness that something was not ‘quite right’ typically culminated in another crisis moment when, after a thorough assessment, they were informed about the probable psychiatric diagnosis or label which accounted for the mental changes they observed in their loved one. To my mind these parents were suffering too. After the diagnostic pronouncement, the parents needed to navigate a new path: that of caregiving for an adult child with mental illness. I observed first hand, that emergent mental illness could threaten a young adult’s transition to independence and that it could potentially elongate the phase of active parenting. I witnessed this shattering experience many times in my clinical practice with parents, and certainly hoped (and honestly often prayed) that this would not happened to my own daughters. It was to me, seemingly an aversive experience with which, I would just as soon not have to deal.

However, I also observed parents who had found their caregiving experiences transformative and seemingly affirming of their strengths and resilience. Through my own experiences and observations, I remained convinced that there was more to know about this experience. Sandler (2001) suggests that

> In order for health professionals to understand how to assist people undergoing adversity and how to prevent long-lasting and damaging effects on the self, two key dimensions must first be understood. First, we must come to understand the nature of adversity itself and second to

> understand the resources that people call on to be resilient in the face of adversity (p. 22).

I agree that there is more we must come to understand when parents encounter difficult challenges. I remain convinced that an interpretive approach was well suited to glean a fuller understanding of the parents' experiences with FEP in their young adult children. The great strength of an interpretive approach is its familiarity with real people in real situations and in coming to understand their day-to-day experiences. Such an approach provides insights into the experience from the very people who live it. Their values, fears, wants and even preferences can be illuminated in their own words. Such information can be invaluable in constructing interventions and supports that are individualized and unique to their situation (Munhall, 2012). In addition, according to Greene (1998), the personal meaning of lived experiences highlighted in an interpretive phenomenological study, can be a more powerful persuader than quantitative data in changing clinical practice.

A Narrative Tale

I also looked at the potential of conducting a narrative study (Sandelowski, 1991; Frank, 2009; Duffy, 2012). I thought, "how simple", I collect the parents' stories and with the aid of a computer program find themes and report my findings. The collection of stories, as a source of data, assumes that the narratives are purposeful, reflect underlying meaning and have meaning to the teller (Sandelowski, 1991; Frank, 2009; Duffy, 2012). However the more I read about the narrative method, the less comfortable I was with this approach for two reasons: 1) could I, given my experiences, remove myself sufficiently from the research process to prevent undue influence upon the co-construction of the story (Stevens, 1992); and 2) would a narrative study answer my specific question, i.e., “How is first episode psychosis experienced by parent caregivers of young adults with emergent psychotic illness?” From a symbolic interactionist perspective, the narrative approach, while able to provide a rich description of meanings and symbols that drive human thinking, action and interaction, would potentially uncover individual contextual differences and not essentially capture the emotions, moods or other psychological factors which come into play (Ritzer & Goodman, 2004; Smith, 2007). The knowledge I might glean from narrative inquiry was more likely to provide more insight into the social world of parents rather than understand the meaning of their lived experience (Duffy, 2012). Although this contextual knowledge is also needed, and I suspect could be a fruitful subsequent focus of future analysis, it was simply not going to provide an answer to the question that ignited my passion for this inquiry with parents at this time.

To be Grounded in Theory

Conducting a grounded theory study was another possibility I considered. Grounded theory is an approach used to explore the social processes that present within human interactions. The aim of grounded theory research is to develop a theory about dominant social processes rather than to describe a particular phenomenon (Speziale & Carpenter, 2007). The research method involved in grounded theory approaches to nursing knowledge development is linked directly to symbolic interactionism. Unlike quantitative research, which starts with a theory, the grounded theory method generates a theory in a specific substantive area. In approaching my research I would have to engage in precise procedural steps, inductively derived from a phenomenon. That is, “a grounded theory is discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon” (Strauss & Corbin, 1990, p. 23). Although this approach may have provided me with an understanding of the process involved in parents’ adaptation to the caregiver role for their young adult son or daughter experiencing FEP, it would not provide a clear understanding of the meaning of this lived experience. Grounded theory is particularly useful when little is known about the area to be studied, or when what is known is from a theoretical perspective that does not satisfactorily explain what is going on (Wuest, J. as cited in Munhall, 2012). Although a grounded theory approach to my research might identify social and psychological processes in the social domain and identify a theoretical rendering of the phenomenon, it goes well beyond my intent to illuminate the meaning of this lived experience.

Approaching Phenomenology: A Philosophy or a Method?

The experience of parent caregivers in response to emergent psychotic illness in their son or daughter is a particular phenomenon and as such, phenomenology appeared to be an appropriate approach to my proposed research. I focused initially upon reading a number of published phenomenological nursing studies, and the papers and texts of several nurse scholars who write about phenomenology (see for example, Davis, 1973; Omery, 1983; Morse 1991; Rizzo

Parse, 2001; Johnston, 2007; Oiler, 1982; Hallett, 1995; Munhall, 1994; 2007; 2012; Conroy, 2001; 2003 and Benner, 1994). At the same time I began to read widely about the philosophy that underpins phenomenology and rapidly understood that this was anything but a simple endeavour. I sheepishly admit I held certain erroneous notions about the simplicity of phenomenology. I formerly believed that it was a philosophically singular approach and that there was thus a singular methodological framework to apply in rather a cookbook fashion. I suspect my own anxieties about doctoral research led to my desire to find a recipe for success. However, within a relatively short period of time, I came to understand that the phenomenological literature was not only extensive, but far from singular in its philosophical underpinnings, methods, processes and/or approaches. I also found that the different philosophies and the resulting approaches employed in phenomenological research were varied and differed significantly. I soon understood that to undertake a successful phenomenological study was to try to understand more about philosophy. There was no structured formulaic approach, no specific step-by-step method to phenomenology, (although some writers from psychology have attempted to articulate exact methods) (see for example, Colaizzi, 1973; or Georgi, 1970). One notable exception here would be the process of phenomenology as articulated by van Manen (1990). His research process holds to the notion of the hermeneutic circle and the tenets of human science.

Of importance for me, these philosophical differences would indeed have a bearing on my own selection of a philosophical approach to underpin my proposed study. The synthesis of my understanding of both Husserl's transcendental phenomenology and Heideggerian hermeneutic phenomenology is summarized in Table 3.1. I certainly do not proclaim to have become expert in either of these philosophies. Instead, I share the opinion of other authors who suggest that both Husserl and Heidegger are notoriously difficult to read, because of the dense German language used, coupled with varying translations (McConnell et al., 2009). However, I believe I have read enough, mainly through using good secondary source translations of original texts (Large, 2008; Collins & Selina, 2006; Gorner, 2007; Leonard, 1994; Harmon, 2007; Dreyfus, 1991; Macmurray, 1999; Moran, 2001;Moran & Mooney, 2002) that I am cognizant of the fact that no singular phenomenological philosophy or method can be simply applied.

Table 3.1 Comparing Husserlian and Heideggerien Phenomenology

Husserlian Phenomenology	Heideggerian Phenomenology
Transcendental phenomenology	Philosophical Hermeneutics Hermeneutic phenomenology
Epistemology	Existential -ontological
Epistemological Questions of Knowing	Questions of experiencing and understanding
How do we know what we know?	What does it mean to be a person?
Cartesian duality Mind/body	Dasein
A mechanistic view of person	Person as self interpreting
Mind-body lives in a world of objects	Person exists as a being in and of the world

Ahistorical	Historicity
Unit of analysis is the meaning given subject	Unit of analysis is the transaction between the situation and the subject
What is shared is the essence of the conscious mind	What is shared is culture, history, practice, language
Starts with a reflection of mental state	We are already in the world in our pre-reflective selves
Meaning is unsullied by the interpreter's own normative view of the world	Interpreters participate in making data
Participants' meanings can be reconstituted in interpretive work by insisting that the data speak for themselves	Within the fore-structure of understanding interpretation can only make explicit what is already understood
Claim that adequate technique and procedures guarantee validity of interpretation	Establish own criteria for the trustworthiness of data
Bracketing defends the validity or objectivity of the interpretation against self interest	The hermeneutic circle (background, foreground and pre-understanding)

(Koch, 1995)

For researchers who are prepared to put effort into the conversations and the subsequent interpretive synthesis of large amounts of data, phenomenological approaches to human science provide a perspective that has the potential to clarify and illuminate important human issues (van Manen, 1990; Munhall, 1994; 2007; 2012; Hallett, 1995). For me the experience of parent caregivers in response to emergent psychotic illness in their son or daughter is an important human issue which invites illumination of its meaning. Additionally interpretive phenomenology can serve to highlight the focal caring practices of parents as they provide support to their ill son or daughter.

Entertaining Husserlian Phenomenology

Initially, believing that I was following the lead of many other nurse researchers, I aimed to use Husserl's philosophy that described phenomenology as transcendental (Husserl, 1969). Central to Husserl's transcendental phenomenology is the study of phenomenon as they appear through consciousness. Husserl noted that subjective experience provides the meaning of knowledge. Within a Husserlian approach to phenomenology, the researchers' attention is directed towards the participants' subjective perception of their own experience (Koch, 1995). Husserl aimed to articulate an approach that would permit philosophers to understand the essences (structures of consciousness) of a given phenomenon and to determine the role these essences play in determining the sense of it all (Dreyfus & Dreyfus, 1987). An assumption specific to Husserl's philosophy was that experience as perceived by human consciousness has value and should be an object of scientific study (Lopez & Willis, 2004).

> Husserl believed that subjective information should be important to a scientist seeking to understand human motivation because human actions are influenced by what people perceive to be real. As human beings generally go about the business of daily living without critical reflection on their experiences, Husserl believed that a scientific approach was

> needed to bring out the essential components of the lived experience specific to a group of people (Lopez and Willis, 2004. p. 727).

According to Koch (1995), it was Husserl who introduced the concept of life-world (original German word: *Lebenswelt*) or lived experience. He claimed that this life-world is not readily accessible because it constitutes what is taken for granted or those things considered common sense. The researcher using Husserlian phenomenology always asks about the meaning of the human experience and attempts to discover and describe the basic rules of experience. Reality is found in the life-world (Koch, 1995). Husserl also notes that knowledge stems from conscious awareness and that the mind is directed towards objects. Dreyfus (1989) claims that Husserl's work represents the ultimate notions of Cartesian dualism; that is, our basic way of encountering things is as subjects directed towards objects.

Three notions appear to dominate Husserl's (1969) phenomenology: intentionality, essences and phenomenological reduction. Intentionality describes the directedness of the mind, and that our own conscious awareness is one thing of which we can be certain (Koch, 1999; McConnell-Henry, Chapman & Francis, 2008; Gorner, 2007). This suggests that we build knowledge through conscious awareness. Husserl also noted that it was important to 'return to the things themselves' and to the essences that constitute the consciousness and perception of the human world (Spiegelberg, 1960). In this way, Husserl's phenomenology would describe the ultimate structures or essences of consciousness and in so doing determine a universal truth (Large, 2008). However, Husserl not only calls for a science of essences, he requires suspension of one’s unquestioning pre-philosophical or natural attitude. This means that in order to take on the appropriate philosophical attitude to see ‘what is there’, one must engage in a process of phenomenological reduction or epoché. This means that it is essential for the researcher to shed all prior personal knowledge to grasp the essential lived experiences of those being studied. This is also called bracketing (Hallett, 1995). Bracketing involves the researcher holding in abeyance ideas, preconceptions, and personal knowledge when listening to and reflecting on the lived experiences of respondents (Dahlberg, Drew & Nystrom, 2001). Bracketing then is seen as a means by which the natural world can be reduced to a transcendental consciousness and only phenomena remain. Husserl’s approach examines the world pre-reflexively, suggesting that in order to expose the ‘lived experience’ it was first necessary for the researcher to put aside any preconceived ideas (McConnell-Henry et al., 2009). In this view reality is considered objective and independent of history and context. Husserl believed that there are features to any lived experience that are common to all persons who have the experience. These are referred to as universal essences or eidetic structures and once identified contribute to a generalized description of a phenomenon. Essences then, are representations of the true nature of a phenomenon and result in one correct interpretation of experiences of respondents (Lopes & Willis). The goal of Husserlian phenomenology is to discover and describe the ultimate structures (essences) of consciousness (Heidegger, 2005).

However, the notion of bracketing which is specific to descriptive or Husserlian phenomenology, seemed to me to be an unnatural task to reduce or neutralize the bias potentially created by my preconceived ideas. I wondered about this requirement and felt that, for me at the least, it would not be possible to put aside my personal knowledge and preconceived ideas. After all, this meant putting aside both my personal and professional experiences of families with serious mental illness. I had concerns about having to constantly deny or set aside large parts of my own life-world. My apprehensions about not being able to successfully bracket my ideas, led to an exploration of Heideggerian phenomenology. Heidegger rejects the notion that we are observing subjects separated from the world of objects; rather, he claims we are inseparable from an already existing world (Magee, 1988). Additionally the aim of this study does not fit with Husserlian phenomenology because it would only lead to a description of the essence of the phenomenon. My study is concerned with the meanings parent caregivers give to their experiences with first episode psychosis and the parent's ways of *being-in-the-world.* This ontological focus is most consistent with interpretive phenomenology.

Assessing my philosophical fit with Heidegger

In contrast with Husserl's (1969) epistemological thinking, wherein conscious awareness is equated with knowledge, Heidegger (1927/1962) was interested in moving from description to interpretation: a philosophy of the ontological. He pursued understanding *Being* itself and determined to expand the influence of phenomenological philosophy from epistemological questions into the realm of being, or the ontological nature of existence. What does it mean to *be* (represented by *Being* with a capitalization of the letter B) before looking into what can be known about existence, truth and the nature of reality? (Heidegger, 1927/1962). In Heidegger's seminal work *Being and Time* (1927/1962), he maintains that people's being-in-the-world or the way people exist in relation to their inescapable world must be the focus of phenomenology.

Heidegger asserts that interpretive phenomenology, also called philosophical hermeneutics, looks at how humans are or how humans exist within a world of relationships. "By 'hermeneutics' Heidegger does not just mean the original method specific to the historical, religious, and cultural sciences, but the whole manner in which human existence is interpretive" (Moran, 2000, p. 235). Etymologically, the word hermeneutics descends from the Greek verb hermeneueuen, which means to interpret and the Greek noun hermeneia, which means interpretation (Pascoe, 1996). Modern hermeneutics encompasses the phenomenology of existential understanding, which is evident in the writings of Heidegger. Therefore, phenomenology can provide rich detailed interpretations of unexplored phenomena and it allows the researcher to investigate the totality of an experience from the perspective of those who live it (Speziale & Carpenter, 2003). The interpretive approach to phenomenology can emphasize our situatedness in the *world*.

Heidegger adamantly rejected the notion of the person as subject or a viewer of objects and separate from the world. Therefore, instead of having to lay presuppositions aside, Heidegger included them as legitimate parts of *Being*

(German word, *Sein*). The interpretive phenomenologist then, is included as a legitimate part of the research and as *being-in-the-world* of the participants (Grondin, 1990).

Heidegger, contrary to Husserl's Cartesian notions, described a concept he termed *Dasein*. *Dasein* is the German word for 'being there' and depicts the human capacity to comprehend one's own existence. It is the openness, the '*there being'* in which meaning occurs or is disclosed (Grondin, 1990). For Heidegger, comprehending human existence can be accomplished only in the company of and by understanding one's relationship to other entities in the world, in other words, being aware of one's own being and the possibility of existing *authentically* (Heidegger, 1927/1962. p 68). *Dasein* was a central concept in Heidegger's *Being and Time*, and is the central concern of interpretive phenomenology. That is, who we are, is constituted by the concerns that engage us in our world and is how we interpret ourselves in our practices and ways of engaging socially (Koch, 1995). It is in this practical and concerned engagement with the world that the meaning of *Being* comes to be revealed (Johnston, 2007, p 104).

Heidegger (1927/1962) called our basic activity, *being-in-the-world* as we are constantly adapting to our situations. He argued that humans are always living hermeneutically, that is, finding significance and meaning in their worlds (Dreyfus, 1991). Heidegger's phenomenology clearly emphasizes interpretation rather than description. We are always already in the world and therefore presuppositions cannot be suspended as per Husserl as they constitute the possibility of our meaning or understanding. Therefore, our experiences, in terms of one's background, relationships, culture and social context cannot be bracketed. We come to understand in the present based upon what we have come to know through our past, or *historicity* (past, present and future) and former experiences. Historical understanding refers not only to what is being understood (history), for which Heidegger criticized traditional hermeneutics and historiography, but also to how it is understood as a way of our own *being* in a situation and world *(historicity)* (Nelson, 1986). When we are born into this world we come into a pre-existing world that has meaningful contexts and practices. Over the course of living life in a world with meaningful contexts and practices humans are constituted as they come into an already formed *life-world* (i.e., culture, language, family, community, society, and so on. Benner and Wrubel (1989) suggest that social identity and membership constitutes the person prior to any individual identity and private subjective experience. Given this , bracketing seems to be an artificial task because Heidegger asserts that human beings are always situated in a meaningful context which is impossible to set aside.

Now, understanding that my own experiences and *historicity* did not need to be bracketed within a philosophical hermeneutics approach to phenomenology, I began to delve more deeply into the works of Martin Heidegger and that of his student Hans-Georg Gadamer. Delving deeply is actually an understatement. I found I needed to immerse myself in these philosophical writings and allow them to play about in my mind and *Being*. The reading was anything but easy. In fact at times it was oddly uncomfortable. It felt like steep uphill hiking without proper training or apparel, leading me to feel woefully inadequate and decidedly unintelligent. However, there were other times that I felt it increasingly resonate within me and it ever so slowly became part of my personal outlook. I had found in Heidegger an interesting new lens with which to view and understand myself and by so doing assist in my understanding others. Munhall (2012) calls this process learning to live phenomenologically.

I came to appreciate that in Heideggerian phenomenology the goal is to increase understanding of the meaning of all human experiences and practices (Cohen & Omery, 1994). I also came to comprehend what it means to be a *being-in-the- world*. This meaning was completely subject to the context of my own *Being* in the world. Koch (1995) notes that understanding *Being* represents an existential question that allows humans to question their own existence and ponder the meaning of their *being-in-the-world.* For me, at least since beginning this phenomenological inquiry, this pondering never seems to stop. Music, art, poetry, lyrics, movies, literature and even jokes all tell me something of what it means to be human. As a wife, mother, nurse educator and psychiatric nurse, I am always already in these situated worlds and simply surrender to it. Heidegger's (1927/1962) message is then essentially simple: understanding is never without presuppositions, or *fore-structure*. There is much that one knows or comes to understand without consciously being aware of it. "These pervasive *taken-for-granted* skills, practices and meanings go largely unnoticed by human beings because they both constitute the person and make the world intelligible to the persons creating possibilities and conditions for action" (Leonard, 1994).

Preparing to Dwell with Heidegger

Preparing to study the experiences of parent caregivers from a Heideggerian hermeneutical approach required a fuller understanding of this philosophy. Through my reading I began to familiarize myself with the terms and language Heidegger used to describe various aspects of *being-in-the-word.* In order to pull the Heideggerian philosophical tenets through my study focused upon the experience of parent caregivers, I felt I needed a thorough grounding in his philosophy and in obtaining a better understanding of Heidegger's unique use of words. I tried to immerse myself in Heidegger's writings, which required multiple re-reading. The following sections are intended as a summary of the Heideggerian philosophy and the key concepts that inform my research. The Heideggerian notions of what it means to care and the influence of relationship as perceived by individual parents specifically underpin this inquiry. For Heidegger, we cannot exist separately from our objective world; instead, we are part of it and shaped by it (Annells, 1996; Johnson, 2000).

The World According to Heidegger

The following discussion of Heidegger's philosophy examines several underlying assumptions about being human. Heidegger's analysis of *Dasein* commences with an interpretation of *being-in-the-world.* Concepts comprising this phenomenon include: '*in-the-world'*: the quality of the existence and the uniqueness of '*being in*' or 'present' in our world. In fact a consideration of any one of these phenomena must involve a reference to the other two. *World* as described by Heidegger has a very different meaning from the usual understanding of geographic locale. Heidegger's conception of *World* is the meaningful set of relationships, practices and language we have by virtue of being born into a culture. In this sense, *world* is *a priori*. It is a given in our cultural and linguistic practices and in our history. *World* is the shared skills and practices which we come to depend on for meaning and intelligibility (Leonard, 1994). Heidegger also uses the term *thrownness* to depict his view of the person as *always already situated*. Human beings then are consistently engaged in "working out the possibilities that exist for them, given their having been thrown into a particular culture, familial or historical world" (Leonard, 1994 p. 47). Interpretive phenomenology strives to illuminate the kind of knowing that occurs when one is involved in a particular world and social situation rather than standing outside as an onlooker (Benner, 1994).

Modes of interaction

Heidegger focuses his form of phenomenology upon the origin of knowledge embedded in every day activities. He actually describes three distinct but interrelated ways or modes that we use to interact with our world: the *'ready-to-hand';* the *'unready-to-hand';* and the *' present-at-hand'*. The *ready-to-hand* mode of engagement is most fundamental to *being-in-the-world.* When things are *ready-to-hand* they tend to withdraw from explicit view and are rarely 'present' to us unless they break, go missing or fail to function (Harmon, 2007). Things that are *ready-to-hand* are available for practical use, are handy, and utilitarian. Heidegger's example was a hammer, a tool used for a simple purpose. *Dasein* understands its use within a network of other entities and is understood to have its existence as *ready-to-hand*. It is apart of the individual's existence, is not fully sensed and withdraws from the scope of awareness. *Unready-to-hand* arises for an individual when a difficulty is encountered in that individual's activity (Brandhorst, 1989). Again, using the example of the hammer, if the handle of the hammer were to break, the problem causes a shift into the *unready-to-hand* mode. The broken hammer signals a shift in focus to the problem. The broken hammer then is salient to the new situation. The *present-at-hand* mode is initiated through this reflection on the problem and consequently alters action. Alternate modes of engagement can arise intuitively and may be the result of past experiences in using a hammer with familiarity (Brandhorst, 1989). Heidegger's modes of engagement provide a useful framework for thinking about the onset of problems and challenges encountered when parents experience the first episode of mental illness in a loved one. Interpretive phenomenology can fill gaps in our understanding and offers plausible insights that bring us in more direct contact with the lived world, engaged activities, concerns and embodied know-how and understanding (Plager, 1994).

The Person as a Being

According to Heidegger, meaning is found in "the transaction between an individual and a situation so that the individual both constitutes and is constituted by the situation" (Munhall, 1989, p. 25). Heidegger claims that the most fundamental way to *being-in-the-world* is '*Sorge*', translated as 'concern for' or 'care-for'. *Sorge* is about *Being* and it is about caring for things and other people

(Moran, 2002; Walters, 1995). "In everyday terms we understand ourselves and our existence by way of the activities we pursue and the things we take care of" (Heidegger, 1975, p. 158). Our existence entails that we are to care about others such that it may be humanly impossible and socially unacceptable not to care about someone or something (Benner & Gordon, 1996). "Things show up as mattering to *Dasein* and our activity is directed in a transparent *taken-for-granted* way towards the future, the *for-the-sake-of-which"* (Dreyfus & Dreyfus, 1987, p. 264). Persons are beings for whom things and events have *significance* (or meaning) and this significance may change with context and bring with it a different kind of understanding. Significance is "the background upon which entities can make sense and activities can have a point" (Dreyfus, 1991. p. 97).

Further, it may be that we matter in terms of the things about which we care (Leonard, 1994). To care, then, is more than an emotional sentiment; it is a way to interact with our significant others and nourish our relationships. Parent caregivers are involved in caring for a young adult child with whom they have a close relationship.

The Person as Self-Interpreting

According to Mackay (2005, p. 181), Heidegger believed that there were many ways for human beings to *be-in-the-world* but the most significant way was in being aware of one's own *Being*: a person fully capable of inquiring into one's own *Being* and fully capable of wondering about and questioning one's own existence. Heidegger notes that in the phenomenological view, *Being* is *self* -

interpreting. We are beings who are engaged in our interpretive understanding. Additionally our interpretations are a function of our background, our *being-in-the-world* (Leonard, 1994). Parent caregivers then, are fully able to articulate the nature and significance of their experiences with the emergent psychosis of their young adult son or daughter. Heideggerian phenomenology acknowledges the ability of people to reflect upon the process of their existence while engaged in meaningful activity (Kellet, 1997).

The Person as Embodied

Since Heidegger conceptualizes *Being* as always *in-the-world, Being* is therefore embodied, encultured and located spatially and temporally. We experience the world as humanly embodied. The mind is never separate from the physical body. To Heidegger, there can be no dualist mind/body split. *Being* cannot be reduced to a self-contained material thing. Understanding *Dasein* means to accept a fully embodied *being-in-the-world*. Therefore embodiment cannot be considered separately from *being* and understanding. *Dasein* lives bodily in the world and discovers itself as part of this world (Kellet, 1997; Biley & Galvin, 2007). *Being* experiences both vulnerabilities and freedoms as part of this situated world and the world is revealed to us through our bodies (Leonard, 1996; Merleau-Ponty, 1945/1962/2002). Todres (2007) takes this further and suggests that embodiment is the messenger of that which is unsaid. This suggests, “the said and the unsaid hold a productive tension within which the lived body and all its connections are adequate in intersecting the said and the unsaid” (Todres, 2007, p.20). Ultimately, understanding is predicated on the belief that immediate experience is embodied with organization and meaning and linguistic, social and cultural patterns or characteristics intrinsic to the experience (Dreyfus, 1972). Engaged agency then implies that we have the capacity to act in the world through our embodiment and to make lived experiences understandable (Taylor, 2006). Kellet (1997) suggests that our involvement in caring practices has the potential to reveal meaning that is attributed to our embodied existence. Parent caregivers then are involved as engaged agents in the care for their ill son or daughter. Their caregiving is based upon embodied intelligence or 'knowing how' the world works through a united mind and body (Conroy, 2001, 2002; Taylor, 1993).

Awareness, the world, and the body are intricately interwoven and engaged with one another. Alhough we can perceive things partially, from a particular perspective and from a particular place and time, this does not diminish the reality of what we see (Merleau Ponty, 1961/1998). There is no other way to perceive reality than from a relative, unique perspective. All that we perceive or understand implicitly is connected to its *background*, (the 'place' where mindless everyday coping skills, discriminations and practices, into which we are socialized, are situated), its environment and to the web of meaningful relationships through our *being-in-the-world*. Obtaining an interpretation and understanding of the way that parent caregivers perceive the first episode psychosis in their young adult child will elicit what might as yet remain hidden.

The Person in Time

As one of the two central concepts in Heidegger's *Being and Time,* time is considered a fundamental structure in human existence. Heidegger notes that interpretation requires grounding in time. However Heidegger is not referring to time in the typical linear way in which one usually speaks of time. This is not like the time on your watch or on the calendar. Heidegger (1927/1962, p. 39) used the term "*temporal determinateness*" to describe how in a moment of time, a limited number of possible standpoints are disclosed. Time is a vantage point from which one can view certain matters, and to ask and answer appropriate questions about them. The experience of time is fundamental to the understanding of *Being* and ways of being (Mackay, 2005). Heidegger considered the person to be temporally situated *in-the-world* and noted temporality as the ground for our awareness of existence, allowing past, present and future to be experienced as a unity. The experience of this unity means that what is experienced in the present is congruent with what has been experienced and what one expects will be experienced in the future and that awareness of them as unified is as one (Heidegger, 1927/1962; Mackay, 2005).

Heidegger also elaborates on the structure of time. Time is structured into care or concern (*sorge*). As time is *Being's* context it experiences all three temporalities: 1) *thrownness- Dasein* is already in the world, dealing with what it receives from the past; 2) *projection*- living now its projections onto future possibilities -*Dasein* is always ahead of itself and never entirely all there at this moment because its *being* encompasses *not yet;,* and 3) *fallenness- Dasein* is preoccupied with the world in the present dealing with current concerns as they arise in the *nows* (Heidegger, 1927/1962). Time then is the basic form of all experience and understanding is a reciprocal activity, where the present can only be understood in terms of the past and the past in terms of the present and so on (Conroy, 2003; Kellet, 1997). We exist beyond the literal here and now. Parent caregiver's experiences must, then, reflect their understandings in the present context having been informed by the past and the possibilities they perceive in moving forward in the future.

Dostal (2006, p.126) suggests that "time flows ineluctably towards the future; it is not reversible". This is of what Heidegger speaks when he describes *Being* as always *going toward death* (Heidegger, 1927/1962). "Death is something distinctively impending" (Heidegger, 1927/1962, p. 294). Although one would hope that parent caregivers will not be focused upon the possibility of immanent death of themselves or of their young adult child with early psychosis, this *going towards death* is a universal experience and affects one's perception of the here and now. Death is inevitable. Rather, an authentic being toward death must make death "understood *as possibility*, cultivated *as possibility*, and endured *as possibility* in our relation to it" (Heidegger, 1927/1962, p. 170). The proper relation to death is essentially a self-relation that discloses *Dasein* to itself and deepens and intensifies the structure of care. It is essential to this relation that we understand death as possibility.

The Person in Space

The caregivers' *being-in-the-world* is also situated in space. For Heidegger, *being-in-the-world* is not only temporal is also spatial. The concept of space identifies the situatedness of the person in both time and place. Spatiality grounds the person in a location. Heidegger (1927/1962, p. 171) calls this special situatedness, *the-there.* From the position of *the-there,* the person is either bringing something close to them (*here*) or experiencing it as remote *(yonder*). *Dasein* is said to have a tendency to closeness although this is not about a measure of distance, rather this is about what matters or what is of concern to a person (Heidegger, 1927/1962, p.138). Space is also structured into care or concern *(sorge*). What is brought to the *fore-ground* and what is relinquished to the *background* of the person has to do with the situatedness of the *being-in-world*. For example, what a parent caregiver brings close (that which shows up as mattering or counting in relation to our practical affairs), and what is experienced as inconsequential (Heidegger, 1927/1962). The situatedness of parent caregivers affects what concerns them.

Interpretive Phenomenological Inquiry: Entering the Hermeneutic Circle

Overall Heidegger disregards empirical science, promoting instead the subjective nature of human existence. Heidegger also believed that people are interpretive beings by nature. As an ontologist, Heidegger asked questions that he thought would lead to uncovering the meaning of *Being*. He viewed *forestructure*, (prior knowledge) as a pre-requisite of sorts to assist phenomenological researchers in asking ontological questions (Heidegger, 1927/1962). Therefore, Heideggerian phenomenology recognizes and affirms the important contribution of the researcher's own experiences. Given that interpretive phenomenology fosters a profound interpretation of the experience understudy (Conroy, 2003) and the fact that parent caregiving, in response to first episode psychosis, is a complex phenomenon with social dimensions, Heidegger's interpretive phenomenology is an appropriate philosophical approach for my study. Insights into parent caregivers of young adults with first episode psychosis and the meanings they give to their experiences may improve the care provided to them.

As I understood more about Heidegger's ontological view of the world, I also learned more about interpretive phenomenology. I felt confident that such an approach would lead to an understanding of the meaning of parental caregiving in response to first episode psychosis in their young adult son or daughter. I then searched for a method or process that would guide me in this qualitative research endeavour.

Selecting a Pathway for Interpretive Phenomenology

It is through the Heideggerian ontological exploration of a parents' being-in-the-world, of Dasein, that the goals of this research study were met. To do this I utilized Conroy's Pathways for Interpretive Phenomenology (2003) to frame the study design. Conroy's pathways or method was specifically designed to complement and incorporate Heideggerian philosophy into the research design. Conroy contributed to nursing knowledge by developing what she termed research pathways based upon the Heideggerian philosophy of interpretive phenomenology. Conroy suggests that within an interpretive phenomenology there are at least three foundational facets: (i) an openness to change and input from respondents throughout the study; (ii) active contribution of respondents to the hermeneutic research circle or spiral; and (iii) built-in ongoing reflection and interpretation by respondents and researcher within six practical Research Aspects. Conroy notes that the six Research Aspects include:

> (1) attending to footprints and concurrent preliminary interpretation;
> (2) in-depth interpretation;
> (3) second reader introduction to the narrative footprints;
> (4) paradigm and paradigm shift identification;
> (5) exemplar development;
> (6) principle development.

The spiraling Research Aspects are depicted in Figure 3.1. Interpretation is integral to each Aspect. Participants' stories shared within conversation serve to ignite the process. This process was a co-created meaning between the individual participants and me. This is true for all aspects of co-creating interpretations within the hermeneutic spiral. Within the spiral both researcher and participant build on their background interpretation as each reflects and interprets what is happening within and across the narrative and conversation sessions (concurrent interpretation). The hermeneutical ripple effect of the spiral is said to be dynamic, impinges on others' interpretations, and over time changes the understandings of all (Conroy, 2003, p. 14).

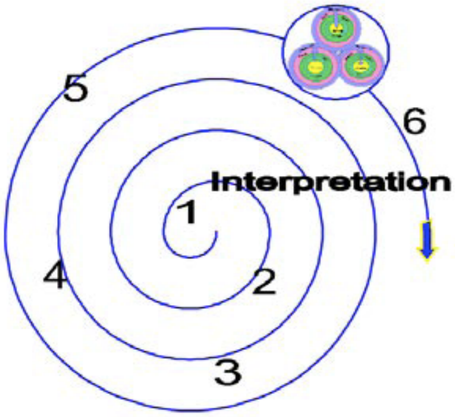

Figure 3.1 Pathways for Interpretive Phenomenology

> “Interpretation spirals outward to include second readers as they gain access to the narrative, and make their contribution. Footprints are interpreted and interpretation leads to more footprints. The researcher continues to expand the interpretation: (1) through repeated visits to the original footprints; (2) by making connections with other participants’ narratives; (3) through notations made in ongoing logs; and (4) by consulting documentary evidence including contextually relevant publications. (5) Reflection upon the process, documented in a Decision Trail Log gradually coalesces the theoretical and the practical in an (6) ongoing reflection-and-action spiral which moves the research onwards”. (Conroy, 2003 p. 14)

Stretching the Hermeneutic Circle into a Hermeneutic Spiral

Human beings as circular beings are always in the world that presupposes understanding. Our world is always already meaningful and intelligible, and our activities are constituted by and make sense in the world. We are in what Heidegger (1927/1962) calls the circle of understanding (p.195). The hermeneutic circle is a metaphor taken from Heidegger to describe the experience of moving dialectically between the part and the whole (Koch, 1996). As Heidegger (1927/1962) commented on the hermeneutic circle:

> In the circle is hidden a positive possibility of the most primordial kind knowing and we genuinely grasp this possibility only when we have understood that our first, last and constant task in interpreting is never to allow our fore-having, fore-sight and fore-conception to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out the fore-structures in terms of the things themselves (p.153).

Thus, Heidegger's position is that interpreters participate in making data precisely because the hermeneutic circle cannot be avoided. Co-constitution demands that primary data be regarded as contextual life events with the respondent and the researcher's perspective specified (Koch, 1995). All claims to understanding made from a given set of fore-structures cannot be eliminated. The hermeneutic circle then, refers to the flow of understanding that takes place through being-in-the-world. It refers to the back and forth movement between partial understandings and the more complete whole (Mackey, 2005).

"*Interpretation functions as disclosure, disclosing what is already there*" (Heidegger, 1927/1962, p. 198).

Conroy (2001, 2003) suggests that the hermeneutical circle is by nature a closed loop. She suggests (drawing reference to Heidegger's comments in *Pathmarks* (1955/1999, p.310) which refer to the circle being a concealed spiral), that loosening the circle and having it form a spiral releases interpretive inquiry from a closed loop. "The hermeneutical spiral 're-presents' the spiraling process of interpretation where the interpretations of a group of people build on each others' understanding over a period of time" (Conroy, 2003, p.9). This release from the closed loop invites an expansion of the research process to include interpretation by others rather than just the researchers and the participants. Conroy's conception broadens the scope of possible interpretations by loosening the circle. This is an iterative process of data synthesis in which the researcher moves back and forth between individual elements of the text and the whole text in many cycles.

The hermeneutic circle was similarly conceptualized as a hermeneutic spiral by Reason & Rowen (1981) who also wanted to point out the interpretive activity of moving back and forth in repetitive cycles. Conroy makes another important suggestion to enhance interpretive inquiry in keeping with Heideggerian philosophy especially as it is re-conceptualized as a spiral. She notes that in Benner's (1994) approach researchers are directed to look for themes, paradigms and exemplars. Although Conroy (2003) recognizes that:

> All three constitute ways of thought and/or action, implying consistency within any given example or person of a recurrent thematic way of thinking. However it is also important from an interpretive approach to seek out modalities and fluctuations in any one person's way of thinking. This would include how people incorporate and respond to their unsettled sense of existence in the world and is consistent with Heidegger's thinking about Being, time and historicity (p.3).

Moreover, Conroy (2003) goes on to suggest that researchers should look for paradigm shifts, not just for paradigms. Interpretation of a paradigm shift reflects the non-static nature of our existence and the movement is consistent with the hermeneutic spiral. This notion moves the researcher beyond any notions of life being static and is clearly in keeping with Heidegger's assertion that our existence has elements of *historicity* (past, present and future), which shape and inform our lives and as we shape others. This conception of movement stimulates interpretive questioning regarding any shift in thinking and how it may have been provoked. The paradigm shift is said to be vital in exposing the "hermeneutic turn" (Hoy, 1993). What I find fitting about this, is that it denotes what I too have come to experience within this research process. Hermeneutic interpretation has notions of movement, turns and sometimes even feels like one is hiking uphill.

To allow for interpretation in a spiraling fashion Conroy (2003) conceptualized the Hermeneutical Principles for Research (HPR). Conroy's principles are listed in Table 3.1, and expand upon suggestions for hermeneutical research suggested previously by Addison (1992), Benner (1994), Leonard (1994), and Plager (1994). Conroy notes that the primary concern for developing the HPR was the underlying goal of engaging in the questioning of the research process. These aims are certainly in keeping with a hermeneutical inquiry. She also attempted to entrench or embed a concerned, engaged standpoint within the research process. I expand more fully on the use of the pathways and principles as applied within my research in Chapter Four.

Table 3.2

HPR #	**Hermeneutic Research Principles Defined**
1	Seek understandings of the participants' world of *significance* through immersion in their world (Addison, Benner)
2	Make explicit the shared world of understanding between the researcher and the researched
3	Immerse oneself in the hermeneutical circle throughout the research spiral
4	Make explicit the immersion of the researcher in the hermeneutical spiral
5	Draw out what is hidden within the narrative accounts and interpret them based on *Background* understandings of the participants, and the researcher
6	Enter into an active dialogue with the participants, the trustworthiness checkers, the narrative itself as spoken and written (Addison)
7	Maintain a constantly questioning attitude in the search for misunderstandings, incomplete understandings, deeper understandings (Benner, Addison)
8	Move in a circular progression between parts and the whole, what is disclosed and hidden, the *world* of the participant and the *world* of researcher (Leonard)
9	Engage the active participation of the participants in the research process: the implementation and the interpretation (Plager)
10	Encourage self-reflective practice by the participants through participation in the research and through offering a narrative account of the researcher and interpretations
11	View every account as an interpretation based on a person's *Background* (Plager)
12	View any topic narrated by the participant as significant at some level to the participants
13	Deem every account as having its own internal logic; whatever is brought to an

	conversation is *significant* to its bearer, consciously or not
14	Access and make explicit participant understandings through their own modes of existence, mode of engagement while being sensitive to one's own modes of existence and of engagement and foregrounding
15	Be aware of one's own use of coping tools in any of the modes of existing.
16	Engage in the spiral task of hermeneutical interpretation along with the participants
17	Keep track of movements in understanding (Benner)
18	Work with participants to see which points are salient
19	View interpretive phenomenology as an interpretation of participants' interpretation
20	Look beyond the participant's actions, events and behaviour to a larger *Background* context and its relationship to individual events (Addison)
	Adopted from Conroy, S. (2003). A Pathway for Interpretive Phenomenology *IJQM*,

Embracing the notoriously complicated

Conroy's Pathways were developed and tested when she approached her own doctoral research with healthcare students and healthcare educators. The framework of HPRs was conceived as something that beginning interpretive researchers, like myself, 'could hang their hat on' until the research process begins to flow for them. Conroy cautions that the process may at first glance appear linear but this is far from her intent. "The linear impression belies the complexity, seamlessness and flux inherent in interpretive research and risks trivializing interpretive work" (p. 5). I selected to make use of Conroy's hermeneutic pathways and principles within my own research for two reasons: 1) so that these principles have another opportunity to be utilized beyond that in her original work; and 2) so that I might also benefit in a practical way from my mentor/mentee relationship with Dr. Conroy. This allowed me to engage as a novice interpretive researcher with someone more expert who had previously traveled this path. This proved to be an excellent learning opportunity and substantially enriched my own understanding of Heideggerian philosophy. Our scholarly partnership affirmed that ideas from Heideggerian interpretive phenomenology would indeed guide my methods and serve to enrich the synthesis of my findings (Conroy & Hamilton Wilson, 2012 manuscript in review).

Approaching Interpretive Phenomenology with Attitude

Although I began my doctoral education and research with the idea of finding a formula or step-by-step recipe for phenomenology, I now know I was mistaken. From my current understanding, I don't believe we can study the meaning of being human in a holistic way unless we study what humans say, what humans do, how they interpret their experience and what meanings they attach to the experience. Munhall (2012) is emphatic about the nonlinear nature of this process:

> To be true to the philosophy of phenomenology we must follow the thing itself wherever and whenever it appears, while being attentive, conscious and alert to its appearance or concealment. Know that with appearance there is possible concealment as well. Explore that and all its possibilities. Liberate yourself from prescribed steps. Methods can place you in a in a formula where you cannot wander outside, and that crucial

> limitation….will handcuff you and keep you from the spontaneous recognition of the appearance and the crucial exploration of the unforeseen. One must be free to journey where *Being* reveals itself (p.119).

Although I suspect any novice researcher likes the notion of "steps," phenomenological inquiry requires that the inquirer "let things come as they appear, reflective of being in the world and open to what appears" (Munhall, 1994, p. 47). So studying the meaning of the lived experience of parent caregivers of young adults with emergent psychosis was dependent upon my philosophical assumptions rather than on a linear method. Similarly, Conroy's hermeneutic pathways and principles were not a literal method leading to data generation and synthesis; rather they were a useful means or a reminder of sorts to remain open to questioning and consistently remain alert to the meanings portrayed by parent caregivers and to turn and re-turn my attention to meaning.

Commencing the journey, first footprints on the pathway

Having made the commitment to pursuit a Heideggerian interpretive inquiry guided by Conroy's *Pathway for Interpretive Phenomenology (2003)* and to use Conroy's (2003) Hermeneutic Principles for Research (HPR) throughout the concurrent gathering and synthesis of data, I began to familiarize myself further with Conroy's pathway.

Attending initially to Conroy's pathway, helped to provide me with a map of sorts that served to guide my movements in and out, and backwards and forward in the spiraling interpretive process. This approach to interpretive phenomenology as guided by Heideggerian philosophy has by necessity included concerned accompaniment from Dr. Conroy who has previously travelled the interpretive phenomenology research path. In this chapter I articulated the philosophical foundations, which underpin Heideggerian interpretive phenomenology and also disclosed my thinking regarding its selection as the best approach to answer my research question. In Chapter Four I describe Conroy's Pathway for Interpretive Phenomenology as I applied it.

CHAPTER FOUR

A nation's culture resides in the hearts and in the soul of its people. Gandhi

Interpretive Phenomenology: As Applied

This chapter commences with a brief review of the purpose of my study and the questions which guided this research inquiry. I include discussions around the following areas: a) rationale and description of the selected research approach; b) description of the research setting and sample; c) overview of the research design and the pathway as I applied it; d) methods of data generation; e) synthesis of data; f) ethical considerations; and g) trustworthiness or rigour.

As stated previously, the phenomenon of interest is the meaning of the lived experience for parent caregivers whose young adult child has been newly diagnosed with emergent psychosis. I used Conroy's (2003) *Pathways for Interpretive Phenomenology* as a guiding approach to keep the inquiry process aligned with Heideggerian philosophy. The aim of this interpretive phenomenology is to value the perspective of parent caregivers in order to gain an understanding of the lived experiences of providing care to a son or daughter with first episode psychosis. This experiential understanding is not yet present in the literature.

The following questions guided this phenomenological inquiry:

- What meaning does first episode psychosis hold for parent caregivers of young adults with emergent illness?
- What is *significant* to them?
- What everyday coping skills do parents use to respond to *anxiety* engendered as they familiarize themselves to the caregiving role?
- How do things count as *mattering* in the world as parents are initiated into the caregiver role within the context of an early psychosis intervention program?

Why Interpretive Phenomenology?

Interpretive phenomenology illuminates layers of meaning inherent in another's experience. Through interpretive phenomenology a researcher enters the world of others in an effort to achieve a wholistic rather than reductionist understanding. An interpretive phenomenologist seeks to understand the meaning of everyday skills, practices and embodied experiences (Leonard, 1994), which generates practical knowledge (Bergum, 1991). To Heidegger (1927/1962) interpretation involves explicit understandings of the meaning things have without our being fully aware of either the things or the interpretation. Essentially, interpretive phenomenology reveals what is already implicitly understood (Cohen & Omery, 1994). Since *Being* is always self-interpreting, the interpretive phenomenological researcher interprets or articulates the way a *Being* copes with what is given in the world.

Heideggerian (1927/1962) philosophy is research work in that it reveals a process of working out the meaning of *Being*. I focus upon the meaning of *Being* parent caregivers. While Heidegger does not explicate a defined method for phenomenological research he does provide some insights about "method and design of our investigation" (p.36). Here, he asserts that access to *Being* is achieved through an account of *Dasein* in their "average everydayness" (p.38). To consider *Daseins* in their everyday state of *being*, structures which are "determinative for the character of its *Being*" can be revealed (Heidegger, 1927/1962, p. 38). I selected Conroy's interpretive phenomenological pathway as it articulated and conceptualized a spiraling process whereby the experience of parents of those with first episode psychosis became the focus of a flow of understanding. Phenomenology requires a turning towards a phenomenon rather than a preoccupation with research techniques (Gadamer, 1976). Using Conroy's pathways also affirmed the notion that "an understanding of a person cannot occur in isolation of the person's *world*" (Walters, 1995, p. 792). Phenomenological research brings together philosophical foundations and methodological considerations in an ongoing dialogue. This dialogue is concerned with both the "pathway" of the research as well as my way-of-being in the research (Conroy, 2003). It is through the Heideggerian ontological exploration (using Conroy's pathway) of caregiving parents' *being-in-the-world* as *Dasein* that the goals of this research study were realized.

Study Setting

Unlike quantitative research that predominately relies upon questionnaires, surveys or objective research instruments, when using interpretive phenomenology, the researcher and participants are co-creators of the meaning of an experience (Munhall, 2012). Such co-construction demands that primary data be regarded as contextualized life events, with the person's and the researcher's perspective specified.

With this notion in mind, the setting for the conversations was at an early psychosis intervention clinic. This community-based regional early psychosis outpatient intervention program was located in Southern Ontario. This highly specialized program offers high quality early assessment and intervention to those with emergent psychosis and concurrently provides education and support for their family members. The program is administered by St. Joseph's Healthcare but remains affiliated with the Department of Psychiatry and Behavioural Neurosciences of a large urban university. The formal access to this setting for my research was facilitated through the medical director (See Appendix B). The medical director also graciously agreed to be named the local principle investigator and to guide this project through the clinical institution's Healthcare Research Ethics Board.

Obtaining Research Ethics Approval

This research was submitted for ethical review to two Research Ethics Boards: it was sent simultaneously to the University of Alberta's Health Research Board (Panel B) through the Health Ethics Research Office electronic submission process and to the hospital ethics board, in south-western Ontario, an affiliate of McMaster University's Health Research Committee to secure research access to the early psychosis clinic setting. Obtaining approval of the two research boards took several months. It was an interesting process, because University of Alberta, Panel B would not provide final approval until, St. Joseph's Healthcare signed off on the approval. Similarly, St. Joseph's Healthcare requested that I submit my letter of final approval from University of Alberta before they would sign off on the approval. Eventually, I phoned the University of Alberta Research Ethics Board and spoke to a kindly support person who was able to resolve this impasse. This personal contact swiftly resulted in letters of final approval from both ethics boards (see Appendix C and D for both REB approvals).

Sampling procedure and participants

A purposive sampling was undertaken of mothers and fathers who had a son or daughter with first episode psychosis and who were currently being seen in follow-up by the specialized EPI team. This sampling was a deliberate attempt to gain access to parents who had personal knowledge of and experience with a son or daughter's emergent psychosis. Participants also needed to be willing to talk about their experiences of caregiving. I included only those parents who had been involved with the EPI program for more than six months but no more than 36 months. This was done to include parents that were potentially beyond the initial crisis of diagnosis but with sufficient experience to articulate their recollections of their son or daughter's first episode psychosis. Participants in the study needed to be adults of age, and have the ability to read and write English in order to provide informed consent.

Sample Size: During the summer of 2010, nine individual parents volunteered to participate. Given the constraints of time and budget for this doctoral study, this sample size was deemed more than sufficient for a phenomenological study. In general the sample size in phenomenological research is small as there is no intention to produce objective, simplified, reductionist concepts of truth (Munhall, 1994; 2012). Rather, the goal of interpretive phenomenology is to understand the complex nature of 'being human' and to come to an understanding about how we think and cope within complex human situations (Smythe, Ironside, Sims, Swenson & Spence, 2007). As anticipated there was an abundance of audio and textual data generated.

Recruitment Strategy After research ethics approval was received for the study, parent participants were recruited from the clinical setting. No active face-to-face recruitment occurred as face-to-face recruitment would have compromised potential participants' right to privacy in the clinic setting. To achieve access to a variety of participants, parents were recruited through information posters (Appendix E) displayed in visible places within the early psychosis clinic and waiting room. I also sent copies of a recruitment letter to each of the care coordinators who work directly with clients experiencing early psychotic illness and the two Family Educators employed within the interdisciplinary team to apprise them of the study. Additionally, before commencing recruitment, I presented the nature and aims of this study at a meeting attended by all clinical team members. This was an opportunity for team members to ask questions and for me to clarify the expectations of potential participants.

If a mother or father was interested in participating, they made contact with me through my University of Alberta email address. This recruitment strategy ensured that the privacy of the respondents was maintained.

Consent process

I made telephone contact with mothers and/or fathers who self-identified their desire to participate in this study. The initial telephone call that I made to the parents had a fourfold purpose: 1) to clarify eligibility to be involved; 2) to tell the parents more about the aims of the study; 3) to begin to develop rapport with potential participants and assure them of my sincere interest in their situation; and 4) to ensure that confidentiality would be upheld during all stages of the research process (see Appendix G; participant screening form). After this initial contact, and once a parent verbally agreed to participate, I scheduled a meeting at their convenience. Immediately upon meeting face-to-face with participants I engaged in discussion about the aims of the study, clarifying the expectations of participants, and answered any questions posed. Following this discussion, the consent form was fully reviewed and the participant signatures obtained.

Description of the conversational setting

All individual parent participant meetings took place in a private office. This setting afforded participants the opportunity to engage fully in the conversation without outside distractions or any interruptions. This office setting within close proximity to the clinic, also offered familiarity.

Participants and Context

Nine parents agreed to participate; three fathers and six mothers all met the inclusion criteria. All participants lived within the Southwestern region of Ontario. I did not actively collect any demographic data from participants, although, through details shared with me in conversations I was able to determine that three married couples (moms and dads seen individually, not as a dyad) and three additional married mothers agreed to participate in this study. For three of the participants, the adult child experiencing first episode psychosis was their only child. All the other parent participants had two or more other children within their nuclear family unit, although not necessarily residing in the parental home. According to parent participants' reports their young adult children with emergent psychosis were diagnosed with either schizophrenia or bipolar affective disorder.

Data Generation: Conversations: Voice Text

In-depth conversations that allowed the parents to share their experiences formed the main data gathering technique in this phenomenological study (Bergum, 1989; Munhall, 2012). In keeping with a Heideggerian approach the in-depth conversations were unstructured and free flowing. The digitally recorded conversations all began the same way, with me making an initial inquiry: "What it is like to be the parent of a young adult son (or daughter) with first episode psychosis?" Data generation took place within this situated context with no limits imposed by pre-set questions. Participants shared their personal experiences in the form of personal stories, which served to ignite the conversations unfolding.

Initially there was one, lengthy in-depth face-to-face conversation with each participant.

All the digitally recorded free-flowing conversations lasted between 45-120 minutes. While attentively listening, I responded minimally in the actual moments of engagement with the participants, I simply offered verbal and nonverbal responses intended to invite further explanation or deeper elaboration of participants' shared stories. I suspect that my clinical expertise as a mental health nurse and my longstanding familiarity with and use of the *Tidal Model of Nursing* (Barker & Buchanan-Barker, 2006) in my own clinical practice facilitated phenomenological conversations. The Tidal model "values and emphasizes the importance of genuine person-centered care that is respectful of culture, creed and which recognizes that belonging and membership are vital to our personal identity as social beings" (Barker and Buchanan-Barker, p.29). When utilizing the Tidal model one becomes accustomed to letting the conversation flow in an unstructured way and to be open to what comes. However, I was keenly aware that my role in these conversations was that of researcher and not that of clinical nurse. My role within this setting was not to provide psycho-education or nursing interventions. Keeping my own role very clear assisted with this.

Throughout all the conversations, I maintained a respectful open stance by actively listening, and being fully engaged in the conversations. I asked probing open-ended questions to elicit the participant's account and engaged in active non-verbal communication through open body language with each parent. This allowed me to fall naturally into the conversation. I maintained an interested, questioning attitude, encouraging participants' active self-reflection within the conversations but at the same time earnestly trying not to interrupt participants and risk limiting the flow (Munhall, 2012). I remained open to anything the participant brought to the conversation. I occasionally shared my thoughts with participants about my own observations or understandings of what they had disclosed. These conversations were immensely engaging; parents appeared to be fully engaged in telling me about their experiences. For most of the parents these conversations with me were the first time they had shared their experiences with someone outside the family. As such, the conversations sometimes took the whispered form of sharing a family secret.

The content of the conversations were intermittently joyous, light, and even humorous. At other times, the conversations became deeply sad and included many poignant and emotionally touching moments. All of the participants became emotional and tearful at least once during our conversations; many cried or even sobbed for brief periods of time. I experienced significant tension at these moments as well, as I attempted to hold back my own tears. I remained consistently aware of the participant's emotional condition (Munhall, 2012). During the participants' tearful moments, I responded initially with silence and subsequently offered supportive or understanding comments. To some, who were actively sobbing, I offered tissues. There were several times during the conversations when I asked the participant if he or she wished to take a break, to stop, or discontinue. None of the participants wanted to do so. Interestingly, all participants said it was helpful to reflect on their experiences, in spite of how painful the recollection was for them.

Other sources of data: Existential investigation

Interpretive phenomenology is a method that allows for the collection of data wherever it is found. Munhall (2007) encourages us to pay attention to the symbols and signs in our environment that speaks to us and tell us what is going on in our environment. For me, this attentiveness certainly included the in-depth textual data gleaned from conversations with participants over time, but it also included data from my own life experiences, personal research journal reflections, anecdotal descriptions from anyone who offered them, etymological sources, and literary, artistic or musical sources, all in an attempt to more fully understand the experience of parental caregiving in the face of first episode psychosis. Munhall (2007) suggests that researchers be sensitive to the presence of material that is important to the study. Eventually a researcher begins to "see it everywhere" (p.168). I added these appearances, insights and connections to the data when appropriate to deepen understanding and to create a full-of-meaning and detailed account of the experience of parent caregivers.

Additional data was also found in the philosophical and phenomenological literature. A close reading and re-reading of this literature was undertaken and included but was not limited to the work of Heidegger, 1927/1969; Gadamer, 1975/2004; Merleau Ponty, 1961 and Taylor, 1989. I also used the Hermeneutic Principles for Research as articulated by Conroy (2003) as a guiding framework to repetitively question the data. Conroy's principles were helpful as prompts and acted to keep my synthesis focused upon Heideggerian philosophy and the meaning of the parents' caregiving experiences.

Preparation of generated data

I listened to all taped conversations immediately after the face-to-face session. The goal of this first listening was to determine if there were any names or identifying details included erroneously in the audio taped conversations. This happened a few times which necessitated that I delete these details before sending the audio-file to the transcriptionist. I had previously negotiated an agreement with an experienced transcriptionist who had consented with her signature to not disclose the content of the conversations (See Appendix H, for signed confidentiality agreement). The transcriptionist also agreed to transcribe the conversations in a timely manner, usually within 72 hours of receipt. In preparing the data, whenever I received the formatted and typewritten files back from the transcriptionist, I began the initial synthesis by checking for accuracy by re-listening to the audio versions while reading the transcripts. I corrected any errors and listened again. When listening to the audio files. I noted participant's tone of voice, silences, the pace of conversation, and the mood they expressed.

Following this second listening, I wrote a short summary or précis of the conversation as was told to me. The first two transcripts and précis summaries were shared with Dr. Conroy to facilitate my development of further skills in conducting conversations for the purpose of phenomenological research and preliminary data synthesis. No attempt was made to discern themes during any of the initial readings. This was simply an attempt to ensure the accuracy of the transcript with the verbal text, and to add annotations to denote silences, pauses and mood and voice tone emphasis. Again, the following is the legend that the transcriptionist used to identify content in the transcribed texts.

Transcription	Legend
…	Pause
[..5s..]	Longer pause [5 seconds]
[laughs] [crying]	Indicates a notable non-verbal feature
He was <u>angry</u>	Voice emphasis

Data Synthesis

My primary source of data in this inquiry was the digitally recorded conversations (voice text) and the respective typed transcript manuscripts (written text). Field notes were completed immediately following each conversation (see Appendix K for sample template). Interpretation occurred simultaneously in the midst of the active conversation (Conroy, 2005), within an active dialogue with the texts by me, and for the initial conversations, with my second reader (Dr. Conroy). As is the case with all interpretive phenomenological studies, data generation and synthesis were ongoing and concurrent. Once I began this study, there was a constant movement of going back and forth between the voice texts, the written texts, existential data and my research logs (see Appendix L and Appendix M for sample interpretive templates).

This research study utilized Conroy's (2003) pathway for interpretive phenomenology. This pathway, which incorporates Heidegger's (1927; 1967) hermeneutic spiral symbolizes the process in which people build upon each other's interpretations and understandings. For Conroy, 'pathways' are possible ways to turn in the research process. Although these are articulated in a tabulated model of six Aspects (outlined previously in Chapter Three), it is in fact a complex spiraling process which encourages researchers to question interpretive synthesis more deeply and to open their minds to unpredictable movement within the participants' textual data. Due to the complexity, seamlessness and flux inherent in interpretive research, the researcher must be open to unpredictable movement between the six Aspects (Conroy, 2003).

In the first Aspect, I concurrently gathered data, began to identify values, beliefs, anxieties and mood, as I initially interpreted and attended to the footprints (voice and written texts). Conroy (2003) used the term "footprints" to refer to a person's contribution to the hermeneutical spiral (p. 5). In this study the footprints blended together through the process of interpretation to create a new pattern of understanding. The second Aspect involved in-depth interpretation. Tentative themes were compiled. The second reader entered the hermeneutical spiral, in the third aspect, by auditing the interpretations and coaching for further depth in subsequent parent conversations. Footprints were interpreted and interpretation led to more footprints. In accordance with Conroy's pathways I continued to expand the interpretation through repeated visits to the original footprints, by making connections with other participants' stories, through reflection upon summaries and notations made in ongoing research logs and by consulting other data sources including texts and aesthetic representations of the interpretive themes identified.

In the fourth, fifth, and sixth Aspects, paradigms, paradigm shifts, exemplars, and then principles were identified. A paradigm is "a strong incidence of concern of ways of being-in-the- world", (Benner, 1994, p.113) paradigm shift is "a change in a way of 'seeing' and coping with the world" (Conroy, 2003, p. 31), while an exemplar is "a case that demonstrates consistency in concerns, meanings, knowledge, and skills common to a participant's experiencing of the world" (Conroy, p. 32). Finally, much later in the research process (within the sixth Aspect), principles were identified and recommendations for health policy, nursing practice, education, and research were formulated. This process was a co-created meaning between myself, and the individual participants and later included that of the second reader. This was true for all aspects of co-creating interpretations within the hermeneutic spiral. Within the spiral, both researcher and participant and then second reader built on their background interpretation and reflections while interpreting what was happening within and across the narrative and interview sessions (concurrent interpretation). The hermeneutical ripple effect of the spiral is said to be dynamic, impinges on others' interpretations, and over time changes the understandings of all (Conroy, 2003, p. 14).

Reflection is an important part of the interpretive process. While reading the various texts numerous times, I engaged in phenomenological reflection, which is a "deeply reflective activity that involves the totality of our physical and mental being" (van Manen, 1984, p. 28, as cited in Bergum, 1991). For me, pausing to reflect, reflecting further as thoughts came or changed or new insights led me somewhere else, shaped, formed and often reshaped interpretations. All of these meandering reflective thoughts were recorded in my research log. Frequently literature, song lyrics and poetry in particular offered representations of the parents' caregiving experiences. Additionally, as several parents spontaneously shared photos of their son or daughter when he/she was well, I also reflected upon these visual images and their context. In keeping with hermeneutical understanding, spiraling interpretations continued to add to the text. Conroy's Hermeneutic Principles for Research (HPR) guided my hermeneutic reflection during all practical Aspects and encouraged me to consider the existential concepts of temporality (lived time), corporality (lived body), spatiality (lived space), relationality (lived human relations) (van Manen. 1997) and mood (Conroy & Dobson, 2005). I consistently reflected on and interpreted the parent's mood and experiences of the body, time, space and relationships to others. Parent's *being-in-the-world* was also interpreted in relation to various historical, social and political contexts.

For many months with the texts of parent caregivers in hand, I read, and re-read them and recorded my own reactions and experiences in response to the transcribed conversations in the transcript margins and in colour coded handwritten reflective (green books) and interpretive journals (pink books). Reflection upon the research process was recorded in a separate decision trail log (purple book) and documents the outcomes of the "reflection-and-action spiral, which moved the research onward" (Conroy, 2003). Through this ongoing immersion, I believe I fully engaged in the experience, attempting to plummet into the depths of understanding the 'Other' (MacIntyre, 1990), to *uncover* what was there (Munhall, 2012), or at least to the best of my ability, to provoke the thinking of all towards the mystery of what 'is' (Smythe, et al, 2007). All interpretation focused upon understanding the meaning of what parent participants shared with me.

Making interpretations, values, beliefs and assumptions explicit after ongoing phenomenological reflection imbues the study intentions and pathways (Conroy, 2003). Interpretation is integral to each of the six practical research Aspects. In later Aspects of the study (Aspects 3-6), the spiraling interpretation moved the research process beyond the immediate concerns of the parent participants towards interpretation of a greater pattern of participants' engagement with the *world* (Conroy, 2003).

In many respects the synthesized interpretive texts, following my phenomenological reflection, wrote themselves. My hand and pen simply acted as the vehicle to give them voice. Eventually, I began by identifying themes that I found within the participants' texts and proceeded to reflect upon and then summarize these in the form of written texts. Themes were identified by reviewing data carefully, and repeatedly. As I uncovered themes, I attempted to isolate verbatim thematic statements before composing a summary for participants. These summaries were written several times in order to capture in more phenomenologically sensitive terms, ideas gleaned during the synthesis process.

Throughout my own phenomenological writing and rewriting process of synthesizing data I returned to my participants in the winter of 2011, to engage in second conversations either in person or via email correspondence. The purpose of the second contact was to obtain feedback about my summative account of the initial conversation and also to obtain feedback on how the identified themes resonated with their conversations with me and with their own lived experience. Participants were invited to make changes or to correct any misperceptions or perceived inaccuracies. Only one participant asked that I add a comment about her disappointment in her husband's involvement with caregiving.

Ethical Considerations

I now turn to a brief description of the main ethical considerations for this study: (a) informed consent; (b) privacy and confidentiality; and (c) risks and benefits.

Informed Consent

During the initial portion of all of the conversations I began by clarifying the intent of the study and articulating the details of participation through reviewing (by reading aloud together) an information letter and a combined information and consent form (see Appendix E and Appendix I)). After a parent verbally consented to participate in a conversation, I requested that they sign the written consent form. Only after the consent form was signed did I initiate the digital recording of the conversation. The consent to continue the process was revisited at the beginning of any subsequent contact or conversation. None of the nine participants requested to withdraw or discontinue participation.

Privacy

The conversations took place in a private soundproof office within the clinic setting. Home visits were not offered to maximize privacy. Every attempt was made to protect participants' anonymity and also ensure that they would not be overheard. Additionally, any research reports will be written using pseudonyms, to protect the identity and privacy of participants. The pseudonyms, which either introduce or end the direct quotations in this thesis, were randomly selected from a list of common Canadian baby names.

Ethical Comportment within the Conversations

Within the conversations, I took an ethical stance, which is informed predominately by the work of Bergum (1989). This stance reflects a relational ethics approach and highlights an approach of respect for the voices of the participants. This approach was actualized through my active listening, respectful interactions, participant review of data, and in the embodied search for understanding. This relationship by its very nature must be one of trust. Developing this relationship was an important part of this process as it is through interaction with others that we come to know what we may safely entrust and what others expect of us (Pask, 1995).

Participant's Wellbeing and Possible Risks

All participants volunteered by their own free will. There were no coercive efforts to recruit participants, nor any deception involved in this research endeavour. All participants were fully informed about the nature and aims of this research process (see Appendix H). Participants were guaranteed anonymity and full control over the conversation process. Participants were also made aware that all conversations would be digitally recorded and that they may withdraw from the conversation and the study at anytime without penalty. They were also apprised of their right to answer or not answer any questions posed by the researcher. Before each of the participants left the conversation meeting they were again asked to verbally affirm their consent. Additionally the participants were assured that publication of any part of this study would not provide information that could unintentionally lead to their identification.

Given the emotional content and sensitivity of the content under discussion at times, the conversation participants experienced a variety of emotions. If a participant appeared distressed in the conversation, I responded to this moment with empathy and asked if the participant wanted to take a break or discontinue the conversation. None of the participants wanted to reschedule or to remove themselves from the study. Similarly none of the participants revealed a need for professional or therapeutic support. Had this occurred, I would have directed them to the Family Educator available to them through the usual resources and support of the clinical team. Other possible suggestions for support, although available, (see Appendix N) were not required. Parent participants may have gained a better understanding of the meaning and experience of first episode psychosis, but aside from that, there were no direct benefits to participating in this study. Participants were reimbursed $10 for the parking costs incurred.

Procedures to Protect Confidentiality

All participants were assured that their names and any other identifying data or participant identifiers would not be accessible to anyone but me. All identifying information was kept in a locked drawer, separate from the study data. The digital recordings and the resulting transcripts and my own research notebooks did not contain any identifying information. The transcriptionist and the second reader were also required to sign confidentiality agreements (see Appendix G. After every conversation, I personally checked all the audio-files for any inadvertent use of names and identifying information; if this occurred, this content was immediately erased prior to being transcribed. Additionally all electronic data was kept on a password-protected computer on a highly secure server at my workplace at Conestoga College. All other research documents, and research journals were kept in a locked filing cabinet. As mandated by the University of Alberta, the research data will be kept for at least seven years after the study is completed. The data will be destroyed once the seven-year period has expired, unless I am conducting a secondary analysis of the data. If a secondary analysis of the data is desired, then subsequent additional ethical approval will be sought.

Evaluation of Trustworthiness

As interpretive research is an artful endeavour by its very nature it is at odds with scientific notions of replicability and validity (Tesch, 1993). However for any research endeavour to contribute to nursing knowledge in a scholarly way it must meet some criteria for rigour, which I choose to call trustworthiness, as I believe the process of evaluating a phenomenological study must contain notions that I, as the researcher, have been credible and trustworthy in my representation of the participants' lived experiences. It was important to utilize strategies that enhanced the trustworthiness of this study. Consequently I adhered to the standard four tests of rigour or trustworthiness of qualitative research as articulated by Lincoln and Guba (1981). This approach to rigour emphasizes an assumption that there is truthfulness or an ideal standard of trustworthiness, which can and should be tested.

1) <u>Truth-value</u>: (credibility) refers to how close the synthesis conforms to what the participants were trying to say. Truth-value was assured by inviting the participants to review their own summaries, and to comment upon my own thematic interpretations. It is the participants themselves who were able to indicate if the interpretation captured their experience and the meaning it holds for them
2) <u>Applicability:</u> (fittingness) refers to how useful the research is considered to be by the participants and the readers of the research. The applicability of this research as been confirmed in two ways to date. First the participants felt it was essential that their experiences be better

understood; upon reflecting upon the summaries provided to them and the interpretation of themes, they articulated satisfaction and agreement with the findings. Non-participants who heard about the preliminary findings of this study when I presented a poster at an international conference also affirmed the need for this research and have expressed an interest in reading the completed research document.

3) Consistency: (auditability) A qualitative study has auditability when another researcher can follow the entire process (Sandelowski, 1986). I kept a decision log that noted all research decisions and activities. Consistency was also affirmed by ensuring equal treatment for all participants (Conroy, 2001) and similar conclusions drawn by an auditor. My approach to data generation was consistent for all participants. Repetition of material served to support confidence in the summaries thematic representation of my interpretations. My second reader was available to help spot inconsistencies or to enhance the depth of interpretation. I determined to ensure that interpretive findings were actual representations of the data and not fabricated accounts. My field notes also augmented the data by describing my observations, reflections, interpretations, hunches, musings, questions for follow up and even moments of my own mood changes. I also kept a personal handwritten journal separate from the data where I recorded anything I felt was relevant to the inquiry. Munhall (2007) suggests that this journaling helps to situate the researcher in the *life-world* of the study. This need to attend

to my own beliefs/reflections and to be aware of my own *being-in-the-world* is considered a valuable contribution to the phenomenological inquiry (Heidegger 1227/1969). Writing in this personal way provided an opportunity for further reflection and offered a deeper, more textured or embodied notion of the experience and showed how my understandings changed overtime.

4) Neutrality: (confirmability) refers to the neutrality or objectivity of the findings. It is impossible for a researcher to step outside the pale of humanness and to adopt a naïve realist posture (Guba, 1990. p. 20).

To further test the trustworthiness of this inquiry I also drew upon the work of Munhall, (1994; 2012). Munhall's evaluation criterion, reflect the notions of Heideggerian philosophy and also speaks to the artfulness of the phenomenological process. The evaluation criteria as proposed by Munhall are: "One P (the symbolic phenomenological nod i.e., nodding in agreement when reading or listening to the study's findings) and Ten R's" (recognition, resonancy, reasonableness, representativeness, recognizability, raised consciousness, readability, relevance, revelations and responsibility) (please see Appendix J) for full descriptions of the criteria and the ways in which my study adhered to Munhall's evaluation criteria). I used these additional criteria to further evaluate the extent to which my study is trustworthy. As with any phenomenological study the spiraling approach that I took to the inquiry was done to withstand the tests for trustworthiness. The use of multiple sources of data and opportunities for observation of the phenomenon as it exists in the *world* around me further helped to elaborate, clarify and support findings.

With any phenomenological study the real test of trustworthiness will be in the hands of the readers who have experience with parental caregiving when first episode psychosis arises, through personal or professional experience. Only future readers will know if greater understanding has been achieved. This is but one understanding, and does not reflect an absolute truth.

In Chapter Four, I described the application of Conroy's pathways to interpretive phenomenology to obtain an understanding of the meaning of first episode psychosis to the parent caregivers of youth with emergent mental illness. I described the various sources of data generation and my spiraling approach to interpretive synthesis. Details about the participants, the conversational setting and the ethical considerations in this study were also described in detail. I concluded this chapter by discussing the tests of rigour that I employed to enhance the trustworthiness of the findings.

Having revealed the philosophical foundations of this inquiry in Chapter Three and the phenomenological pathway as I applied it in Chapter Four, I now turn to Chapter Five, which is the first of four chapters that will articulate the findings of this inquiry.

CHAPTER FIVE

"Life is messy, wear a smock Greeting card expression.

Guilt, Blame and Messiness

The many stories of protection are the focus of this chapter. I initially describe the parental notions of caring as protection. I share parents' concerns for feeling the need to expunge their guilt and confess to self-perceived wrong doings, which they believe may have caused or contributed to illness onset. Following this I bring to light the expectations felt and experienced by parents in our culture and then let unfold parents' experiences when confronting unpredictable events like the emergent psychosis of their young adult children. I use several analogies to aid in interpreting the meaning of the power and limits of the caring protective behaviours employed by parent caregivers. Below, sometimes these are metaphors, published poems, songs, and books. As stated above when studying a phenomenon one wants to see how others have discussed this phenomenon in different ways. A caution though in phenomenology is not to let those interpreted pieces of work stand for the participants in my study. Rather see these as ways others have understood the phenomenon as well as how when we can't go directly to a specific meaning or understanding, somehow we have to go to metaphors to help us on our way to understanding what is happening in my participants' experience (Cameron, 1998). I also include my own poems based on the data.

Uncovering Hidden Aspects of Care

Protective caring practices of parent caregivers of a young adult child who was experiencing a first episode of psychosis were often hidden from view behind a façade of keeping up appearances as “normal”. This protection appeared to be designed to protect the young adults’ self esteem and personhood but also protect a parent from the experience of failure in the social context of parenting. Benner and Wrubel (1989) defined caring practices as “organized, specific practices related to caring for and about others” (p. 408). “These practices are particular, historical, and contextually and situationally elicited and delimited” (Chesla, 1991, p. 450). In the case of parent caregivers of young adults with emergent psychosis, these practices appear to stem from the combined traditions of caring for family and parenting. Concrete caring and protective practices arise from “caregivers unique *backgrounds,* ways of *Being,* skills and understandings” (Chesla, 1991, p. 451). My interpretive challenge was to comprehend how certain aspects of a parents’ *being-in-the-world* open up and close down other possibilities for those in parents’ care. By interpreting parents’ stories of their caregiving I was able to see “complex relations between the situational constraints and demands and the caregiver concerns and actions” (Chesla, 1991, p. 451).

As my research conversations unfolded, the temporal nature of these relationships became very clear. Essentially, there was a story about the ‘before’ and the ‘after’ of the arrival of psychosis which parents needed to share. Psychosis certainly seemed to have particular meaning in the context of *time*. In all the stories the parent caregivers shared with me, the onset of psychosis was experienced as a very stressful event. The *significance* of the emergent psychosis of a son or daughter meaningfully influenced parent caregivers' judgment of the past. "The past that is *significant,* is the past as it appears now" (van den Berg, 1972, p. 79). The onset of psychosis was so momentous an experience to parent caregivers that it affected their view of the past and meaningfully influenced their experience of the present. The emergent psychosis of a son or daughter also raised concerns for the foreseeable future. The present was the lens through which parents re-evaluated the past and held concern for the future. Through the new vantage point of psychosis in a loved son or daughter, the significance of the present is manifest. T.S Eliot poetically expresses the significance of the present.

Time past and time future
What might have been and what has been
Point to one end, which is always present
T.S. Eliot -Burnt Norton

The emergent psychosis was the vantage point through which parents told their stories and shared their experiences. The past was viewed from their present *being-in-the-world* and the future was viewed from the present.

Protecting Possibilities

In our culture, parenthood is a life-long protective role taken on to preserve the wellbeing of children, no matter how old. Protection of someone or something suggests that a caring practice is involved. Heidegger (1927/1969) suggests that when we care about someone or something it calls up *coping*. Care establishes those things that are *significant* in one's life. *Sorge* or care is about

Being and it is about caring for things and other people (Moran, 2000; Walters, 1995). Within a *world* of possibilities, parents act to create a shield of protection around their loved ones; the young adults they care about. A parent's energies serve to protect against hurt, guard against harm and provide a safe and nurturing family and social environment. Although I recognize that there are some children who are victimized by the actions of abusive parents, and for these innocent children my heart literally aches, the vast majority of children are embraced and treated as treasured gifts, to be cherished and are provided with the necessities of life and as much as is humanly possible, protection from harm. Protection is from the Latin word, 'protectio' meaning, to preserve from injury or from harm; it "includes the action of protecting someone or something; the fact or condition of being protected; shelter, defense, or preservation from harm, danger, damage, etc.; guardianship, care; patronage" (Oxford Online Dictionary). Further etymological investigation reveals that 'pro' is a latin prefix denoting prioroity in time or space and means advancing in front. Similarly 'proto' means first (Etymology Online Dictionary). So the notion of parents' protection involves standing at the ready in front of what might happen to their child. However this stance may be very difficult to maintain when the adversary of psychosis looms. Parents cannot stand in front to protect a young adult child from psychosis.

Protection starting at conception

In this day and age of reality television we do not have to look very far to see parental love in action. The hopes for a newborn baby are articulated by every parent featured on "The Baby Story", the popular TV show on The Learning

Channel (TLC) which acts as a video diary of the anticipation of the baby's birth and the loving intimacy of the immediate postnatal period of bonding. Even just briefly tuning into this show, one can easily see and capture an emotionally moving view of the purity of parental intentions to care for and safeguard the infant from harm. For most parents, this safeguarding role, is fuelled by powerful endorphins, (Maté, 2008, p. 154), and drives the desire to provide protection for their child and continues indefinitely. A child gives parents' a sense of hope for the future and immediately engages them in caring and nurturing practices and protective behaviours. This is conceived of as a forever relationship: a relationship in which one enacts skillful caring practices with the aim of enhancing and preserving the child's possibilities.

Sharon, a mom whose daughter developed a mood disorder with psychosis, described her transition to parenting as an initiation into constant worry.

> *The minute I got pregnant, I began to worry. I worried about her all the time. Everything centered on how she was doing. I went from ....being carefree to being concerned about this little tiny baby and realized right then and there that parenting was a huge responsibility. She was a pretty good baby, but I was always afraid I would do something wrong. I did my best, but it wasn't easy.* (Sharon)

Victoria remembers the infancy of her son this way.

> *You know, he was my first child. He was a beautiful big baby. Everyone said he looked just like the Gerber Baby Food baby (smiles and laughs.) I*

> *was so in love with him and enjoyed showing him off. He was smart too. He was our whole world. We doted on him and felt so proud of him. I don't think we could have loved him any more. We watched over him all the time. I always wanted to keep him safe. I worried about him all the time.*
> (Victoria)

Victoria and Sharon's recollections resonated with my own experience. I also remember when I was pregnant with my first child, not long after the titillating and joyous excitement of first coming to understand that my husband and I would become parents, I became uneasy, anxious, suddenly, and acutely consumed with the other more worrisome aspects of my situation. The notion of parenthood charged me immediately with the burden of protection. Parenting, from the beginning, from the first missed period, from before the first whispering flutter of new life felt within, brought with it a responsibility to protect. At first, this meant I had to quit smoking and forgo alcoholic beverages, and to seemingly extinguish all my bad habits for the future health of my unborn child. I had to drink more milk, consume a healthier diet, and get more rest to create the ultimate biological environment for creating a viable offspring with ever more potential. The transition was not an easy one. It was no longer just "me", it was "we". My body and my life would forever be shared with the new life, forming within me. I was charged with the social and familial responsibility to care and to protect. However parents can't protect from this thing called psychosis, it is so alien and different…it calls urgently for a different parenting style and parents have to learn fast.

Vangie Bergum in her phenomenological study of mothers entitled "*A Child on her Mind"* found something very similar. She suggests that:

> The experience of women during pregnancy, birth and nurturance demonstrates how the woman turns toward the child, and how, in this turning to the child (as Other), she comes to a renewed sense of herself (the Self)..… The stories of mothering are sources of moral knowledge. (p. 134)

So for mothers (and one has to assume fathers), their personal background experiences and meanings set up certain possibilities for the kinds of care they can give and preclude other kinds of care. Parents' background meanings, history and concerns comprise their *world* (Dreyfus, 1983, 1986). What matters to parents is set up by this *world* and can only be made intelligible when aspects of this world are partially understood.

The care and protection of their children really matters to parents. LaRossa (1988, p. 88) described this parental vigilance and focused attention to the safety and wellbeing of a child as continuous, noting that someone must continuously be "on duty". Lamb (1987, as cited in LaRossa, 1988) described three components of parental involvement: engagement (time spent in one-to-one interaction); accessibility, (time spent in a lesser degree of interaction but still accessible to the child); and responsibility (time spent physically and mentally with the child; and "being accountable for the child's welfare and care"). Although Lamb was referring to parenting a young child, these same notions of protection appear to be continuous, into young adulthood. When does the parental care and protective role end anyway? Does it?

When parents commit themselves to caring for a child it is an invitation to love and protect forever. The refrain from the popular children's book, *Love you Forever* by Robert Munch (1995) depicts this notion of a parents' loving forever.

I'll love you forever;
I'll like you for always,
as long as I'm living
my baby you'll be.

Robert Munsch (1995)

Indeed most children and their parents share a deep love. This best seller by Robert Munsch shows the depth of that love. It invites reflection on a universal notion of loving forever and according to publisher reports has been purchased as often for children as for adults. Munsch himself has been surprised by its popularity and the way it resonates with all age groups, noting that "It can be found everywhere from elementary schools to retirement homes." The popularity of this little picture book is intriguing. It is an expression of love, and an affirmation that there is nothing a child can do to make parents stop loving him or her. Seemingly, that does not exclude experiencing an episode of psychosis.

No doubt the age of a child changes the ways a parent takes action to care and protect, but does not alter the original intention. In our society we hold, what I believe to be, very high if not impossible expectations of parents. Rando (1986) says, “Parents are to be all loving, all good, all concerned, totally selfless and motivated by the child and his welfare” (p.9). Perhaps it is not surprising that bookstore shelves are full of “how to” manuals and self help books targeting parents who wish to avoid making mistakes. Parents are held to account for the way in which their offspring behave. Parents then are socially and culturally motivated to protect and enhance successful outcomes in their offspring. Parent caregivers’ own background, history with the child, and history with the illness understandings set up what needs they perceive in their ill son or daughter and how they will respond (Chesla, 1988)

More recently, parenting has been described as a “competitive sport”. Peter Stearns (2002), a social historian at George Mason University in Fairfax, Virginia and the author of *Anxious Parents: A History of Modern Childrearing in America,* sums this condition up: “In our society now, a child’s success in school and life has become emblematic of your success as a parent” (p. 37). Our children then, are in large measure a reflection of our parenting prowess. If your adult child turns out well, you get an excellent performance review. You have done a good job. If your adult child struggles to succeed, falters due to illness and/or accumulates failures, your performance review as a parent is severely compromised. The measure of a good parent is culturally determined by the degree in which they adhere to social norms. However, being a perfect parent or even a mediocre parent, no matter how hard one may try, is impossible in the realities of real life. Yet the parents I met in this study held themselves to a very high standard. The presence of psychosis was perceived of as the consequence of parental failure.

Forgive me Father... I must have sinned

> To ask a question means to bring into the open. The openness of what is in question consists in the fact that the answer is not settled. It must still be undetermined, awaiting a decisive answer. The significance of questioning consists in revealing the questionability of what is questioned. (Gadamer, 1960/1989, p. 363)

Despite using the same opening research prompt with all the parents I met, which was " What it is like to have a son or daughter with first episode psychosis?" the majority of parents went right back to their young adults' infancy and childhood to begin to share their experiences. The conversations typically focused upon telling me what it was like to have raised this now-adult child over time. It is not surprising that almost all the parents started their conversations with me by sharing the details of their child's growing up years. They shared the context or *situatedness* of their parenting of this young adult child overtime. In fact often the conversations had a hushed confessional quality to them, and involved parents recalling events that they perceived, in retrospect, were parenting failures on their part. Parents expressed guilt feelings and shared stories of events that they believed might have contributed to the development of psychotic illness in their loved ones. Parents most often blamed themselves in large part for failing to protect their young adult child from mental illness. They all confessed to believing that they might have done more or done something differently. Several parents wished they could turn back the clock and in light of knowing what they now know, (knowing about psychosis), doing things differently. The "If only's " were a constant guilty companion "If only I had .... If only we had seen … If only… Harold, spoke eloquently about his guilt feelings.

> *Yeah, we, we've changed so much and that's another kind of guilt that we feel that probably we moved him around too much. Ah, that's the many guilts, that you feel as a parent and how many things you did wrong and how much is our, ah, yeah, is your, …[stuttering]…your, we are to blame for what's going on now…[10 s]…you blame yourself, if only we had done something differently.* (Harold)

Harold, and his family have traveled extensively during their lives. Harold reflects now upon all the relocations and is quite certain that it caused psychological vulnerability in his son. For Harold, the "If only" was, if only we had not moved so much.

Sharon, too, a mom of a young adult daughter diagnosed with a mood disorder who was pursuing higher education, blames herself for not seeing signs much earlier and experiences guilt for not taking steps to protect her daughter from too much stress.

> *I wish I had said something, you know, I still feel really bad about that, you know, as, as a mother, as you know, um, sometimes you should do what you should do and never mind what everybody else says. But it was*

> *her life. I didn't want to be the one to pull the plug on her career.*
>
> (Sharon)

Sharon admits to seeing many worrisome and concerning signs in her daughter, but also not wishing to meddle in her daughter's life and decisions. She continues to feel guilty about her former inaction and blames herself for her daughter's illness.

Parents frequently gave the impression that they felt the psychotic episode might have been prevented. The content of perceived errors was different for each parent but was present in every conversation. All parents held themselves accountable for having "missed something" which led to this illness outcome. The parents continued to struggle to make sense of this "thing" called psychosis. They assigned blame to themselves and felt guilty for not being able to stave off the onset of this illness. One dad, Thomas says this most succinctly, "I misread him." Thomas holds himself responsible for having, misconstrued his son's needs and having failed to see the "signs". Carol notes, "When I saw her that sick with psychosis, I knew immediately that I had failed her. I knew I had done something really wrong. I am a failure."

> *He was leaving our home for a while and then coming back and then we eventually kicked him out a few times. But through this whole time it was little things he would say to me, like um, you know, about friends hearing voices, and things, and I never really, it didn't take, it was awhile later that he says, do you think that's crazy if somebody hears voices? I go -*

> *you know what? I've never heard voices, but sometimes people that are mentally ill say that it's kind of like your conscience, and that's what I said to him. But I never thought it was him, I didn't dream that he was hearing voices.* (Victoria)

Victoria recalls a difficult number of months watching her son change. She noted that he was not making sense and she believed that it was related to his use of recreational drugs. She noted that he spoke in the third person about hearing voices. Victoria feels she failed him. She blames herself for having failed to understand that her son was hearing voices. She laments not having understood earlier.

The hushed confessional quality, of these guilt-laden statements was powerful. Each of the parents shared their deepest fears. They cried or sobbed intermittently while sharing their anxiety and verbalizing their worry that they had somehow failed, not measured up, missed something, overlooked something important, or failed to get involved at an earlier point. I often felt uncomfortable, or overwhelmed, bearing witness to their pain, and most certainly constrained by the researcher role in not being able to actively reassure them that they are not to blame. I often wished that I had access to a magic wand. I wanted to wave it ceremoniously to rid parents of their guilt. They were obviously holding an accounting of their prior parenting and consistently found themselves lacking. It was particularly interesting, that despite awareness on one level that psychosis is an illness, a biological vulnerability and therefore unpreventable, all the parents had retrospectively assigned themselves some degree of blame in its genesis.

This poem by New York poet, Louise Gluck speaks to the confessional sentiments of the parents and the impression of the past from the vantage point of the present.

Confession

To say I'm without fear--
It wouldn't be true.
I'm afraid of sickness, humiliation.
Like anyone, I have my dreams.
But I've learned to hide them,
To protect myself
From fulfillment: all happiness
Attracts the Fates' anger.
They are sisters, savages--
In the end they have
No emotion but envy.

(Louise Gluck) PoemHunter.com

American poet, Louise Gluck is known for her intensely honest poetry. This one is particularly honest in reflecting the brutality of guilt and its savage attack on happiness in the present. When experiencing guilt, like the caregivers with whom I spoke , it is all consuming and appears to actively reshape their current self-perceptions and identity. Guilt is a constant companion of parent caregivers.

The messiness of life

I know from both my first hand experiences and witnessing the experiences of other family members that caregiving for and protecting a loved one with emergent psychotic illness is a formidable task. Indeed caring for a young adult child with emergent psychosis is messy. Daily life loses its predictable rhythm and the usual everyday order of family life is most often turned inside out. I often envision this as a terrifying hijacking. Reluctant families suddenly find themselves on a hijacked plane being piloted by the mentally ill member, forced into an unwanted journey, with an unknown destination, and always cognizant of the risk of a crash landing, Essentially when those with mental illness lose control of their lives, so do those who love them. In the face of such frightening turbulence is it any wonder that caregivers try to regain some control? Generally people require order. We all try to minimize ambiguity, messiness, unpredictability and disorder (Karp, 2001). While all turbulent times create chaos and messiness, the trauma of mental illness in a young adult child is especially tortuous. Mental illness appears unpredictably and takes unpredictable forms. The order and predictability of daily family life is replaced with messiness and disorder.

Certainly anyone's life can be messy and far from perfect. I suspect messy times are a given in life. So much so that when I recently went to buy a "thinking of you" card for a friend of mine who had been struggling with multiple life stresses simultaneously, that I happened upon a light hearted card with the inscription, "Life is messy, wear a smock". Upon reading this, I spontaneously giggled a little too loud. Unfortunately I think I made the shop clerk a bit uncomfortable, judging from her disapproving gaze. But I couldn't help but appreciate the humour and synchronicity of the moment. Finding that particular card when I had been immersed in phenomenological thoughts of life's unpredictable messes seemed ironic. The emergence of mental illness in a young adult child and the parents who face the daily worry and uncertainty of this experience, know all too well about the messiness of life. For them, it will take more than a bright red vinyl smock, like the one depicted in the greeting card, to keep them free from the untidiness and potential disarray associated with psychotic illness. First episode psychosis of a loved young adult child is always unwelcome, and for the sorrowful parents who live this experience, leads to a yearning for answers. Parents try to find stability, a clear, clean path and tidy solutions to the formidable challenges which they and their ill adult child face. The cultural meanings and practices constitute the family and its members. Being constituted means that the world of meanings and practices into which we arrive sets up who we are as well as how we understand our practices and possibilities (Chesla, 1995).

This puts me in mind of a popular book by Rabbi Irwin Kula, called *Yearnings: Embracing the sacred messiness of life,* which essentially suggests that messiness is sacred stuff. It is indeed an interesting notion, (not one which I easily intuit) but worthy of note nonetheless. Kula thinks that we should embrace all that is untidy and imperfect as "the stuff that keeps us growing" and leads to wonderful opportunities and discoveries. Life's messy challenges can become the vehicle to open us up to more possibilities. But this “mess”-age is not generally accepted let alone embraced as the vehicle for living our humanness. The problem of restoring order becomes that of the parent caregivers. For me as researcher, I was prepared to meet or in my case re-meet the messiness experienced by parent caregivers while encountering the various hues, tones and degrees of human emotion in response to their innermost, intimate pain. I resolved to be open to “what is” happening in these parents’ worlds, to understand what it means to be human and to bear witness to their experience. Parents needed to be understood “as being firmly grounded in the cultural possibilities available to them at the time” (Chesla, 1995, p. 69).

Awakened to “what is”

Coming to grips with the mental illness of a loved one, is a journey fraught with uncertainty and ambivalence (Lefly, 2000) In my own experience when my husband became ill, it was a slow and almost imperceptible process. We were living our lives within its regular rhythm, not attending to anything as being amiss. I felt that all was well until one day when he seemed preoccupied with what others thought of him. I initially dismissed this as fatigue and encouraged him to get more rest. I was not particularly perplexed, as I believe there are many factors that can contribute to feeling uncomfortable within our relationships with others. I thought nothing further of his concern. I kept up my routines and daily work. Then another day, it happened again. We were sitting in the living room and he was suspicious that others at work were taking special notice of him. Given my knowledge of his co-workers, the story seemed implausible. Suddenly, at least for me, the "penny dropped" as they say. I became alerted to something that was amiss, an unusual perception, something different, some thing outside of our life norms. My usual routines and daily activities would and could no longer continue in the same way. My efforts then focused upon sorting out what might account for this change. I suddenly had more questions than answers but I knew without a doubt that something had changed.

The basic way that humans live in the world is in engaged practical activity. Being fully and unreflectively involved in everyday action has been described as being in the *ready–to-hand mode of existence* (Dreyfus, 1991). Engaged practical activity or smooth functioning is the usual way one engages within a day. For me, my smooth functioning failed when I came to recognize my husband's activities as a disruptive shift of my own understandings. There was a breakdown in the smooth flow of practical activity and my *taken for granted* expectations of the situation. In this *present-at-hand mode*, I reflected upon the events (*present-at-hand mode*) and I was faced with reviewing other possibilities.

The moments of clarity, the heightened awareness that something was amiss held *significance* to parent caregivers. The onset of illness symptoms mattered to parent caregivers. Although the stories of the parent caregivers' growing awareness were not identical or mutually exclusive, there was a form of protection and care articulated by almost all participants in this study.

Heidegger suggests that human life is "*factical*", always immersed in a specific situation, involved with its surroundings in a very particular way. This facticity always remains partly obscure. In fact Heidegger goes on to say that the "only way to avoid reducing things to their appearance is to focus on the *facticity* of human life in its environment, where everything has a tacit meaning or function long before we consciously notice it" (Heidegger, as cited in Harmon, 2007, p. 25). I consciously noticed that something was wrong with my husband, only later, after my perception of his usual *everydayness*, changed. This moment brought my personal concerns into sharp focus, inviting an *unready-to-hand* mode of being. Entering an *unready-to-hand* mode of being is a journey, which has many twists and turns. However this journey was not planned for, and certainly not anticipated. Like something which comes out of nowhere and leaves one blindsided, psychosis is just there. It becomes manifest. The journey begins when one least expects it. It is a trip withnout a current passport, no luggage or clothes, and no maps to guide the way. This *unready-to-hand mode* of engagement ocurs when there is a breakdown in our usual coping methods, where nothing works the way it normally does. The tools, like Heidegger's example of the broken hammer, simply stops working as it should. For parent caregivers, their usual parenting approaches are no longer approppropriate for the context. When usual approaches fail they become defamiliarized in anxiety. This anxious mood unfolds when usual coping no longer has effect. We feel the effectiveness pulling away from us, as if slipping through our fingers (Taylor, 2003). Parent caregivers still know how to parent, but their usual approaches no longer have the same effect. Heidegger would opine that this anxiety, of being in an unready-to -hand mode puts us in a position of radical otherness (Taylor, 2003).

For some of the parent caregivers who shared their stories, this moment of angst was seemingly a sudden awareness; for others there was a long anxiety ladden process, of trying to make sense of things. The theme of protection, the actions and desires to step out in front and protect the young adult child, to make things right for him or her, irrespective of the age, was consistently woven throughout all the stories of the moms and dads I came to know.

Psychosis: The unspeakable

Throughout my conversations with parents I became aware of how infrequently they used the word psychosis, or psychotic to describe what their children were experiencing. It was somewhat ironic, that we were sitting within a stone's throw of the Early Psychosis program but parents' use of the word psychosis was almost non-existent. When immersed in the conversations, I sometimes used the word but it was generally not part of the parent caregivers' vocabulary. It remained an unspoken, like something unutterable, having somehow become too powerful to dare expression.

Psychosis is a medical term but it has a lay understanding which brings with it notions of craziness. It is an old word originally from the ancient Greek word *psyche.* The Greeks identified *psyche,* like a breath, considering it to be the ultimate animating principle within man or any other living being. Psyche was the life-breath, the source of all vital activities, ultimately the soul or the spirit of being itself. As per medical convention, the Latin suffix *osis* was added later, denoting a condition or disease. In this way the definition of psychosis becomes a crippling label, describing something wrong with the soul, problems with the life-breath or the spirit of an individual. No wonder this label is not readily within the vocabulary of a loving parent when describing the illness of their young adult. Indeed, a “broken brain” (Inman, 2005) or a chemical imbalance (Hatfield & Lefley, 1997) does sound better, and certainly must feel better than suggesting one’s loved one has lost the source of their vitality, their life breath and their soul. When breath goes, life is completely altered. It brings to mind the suffering of those with chronic obstructive pulmonary disease. Breathing is laboured, insufficient to maintain one’s usual activitiy levels. Overtime the world gets smaller, encapsulated and difficult to navigate. Anxiety predominates. Heidegger would suggest that every understanding has a mood, like anxiety or angst, and every mood brings with it an understanding (Heidegger, 1927/1962). Mood is disclosive. Parent caregivers expereinces of anxiety in response to their young adults loss of vitality and life breath propels them forward and projects a changed future (Smith, 2007)

Bonnie’s son was quite unwell for sometime, before she and her husband came to understand that he was mentally ill. She was able to suggest that her son was “overwhelmed with stress”, “working too hard”, “acting weird”, “feeling blue” and “burnt out.” She never used the word illness or psychosis to describe his situation. She was not unusual. Most of the other parent caregivers also found alternative less worrisome descriptions for psychotic illness. Language was a source of knowledge.

Heidegger would suggest that those things not said contain a powerful message.

> Saying and speaking are not identical. One can speak, speak endlessly, and it may all say nothing. As opposed to that, one can be silent, not speak at all, and in not speaking say a great deal.... Yet what is it we call saying? To experience this, we shall hold to what language itself calls on us to think in this word. Sagan means to show, to let something appear, let it be seen and heard. (Heidegger, 1993, p. 408)

But, Heidegger (1993) goes even further in attempting to understand language as more than a simple communicative tool. Language, according to Heidegger is essential to human beings: “We are within language, at home in language, prior to everything else” (p. 398). At times, it is easy to forget that the mere sharing of words does not necessarily constitute the fundamental act of communicating, of being-with. We must also listen to the silences, give space and time and to let things show themselves in language. Silence is the language of things that we cannot bring ourselves to utter. Each of us learns early in life that language can be used to divergent ends — to wound or to placate, to unveil the truth or to obscure it. Often what remains unsaid, unspeakable or unutterable are matters of grave importance. Psychosis is one such word, which remains concealed in darkness. Caregivers dare not bring it to light. The silence becomes what Heidegger would call *sorge*, or a heavey burden. (Heidegger, 1927/1962) When we take on such sorge we experience the consequences of this burden. It may lead to finding ourelves in uncharted or turbulant waters, being tossed about in a fierce sea.

Don't wake the dragon

Protection can be physical or psychological and is motivated out of a desire to prevent harmful experiences. From my conversations, parent caregivers most often had a notion that something was not right with their loved one for months, sometimes years, before the diagnosis of psychosis was made. During this time period parents related engaging in an abundance of activities, which acted to at least temporarily prevent the situation from getting worse. When repeatedly listening to the digitally recorded stories, I was reminded of the game that my children played when they were quite small. It was a three dimensional game by Parker Brothers called "Don't Wake the Dragon". In the game the Dragon, called Big Snore, snoozes next to the penguin eggs he stole. When it is your turn, you try to race your penguin across the unsteady icebergs to return your egg to your nest --first one to do so wins the game. However, if you land on a dragon space you have to depress a plastic plunger. This makes the ferocious dragon wake up and the icebergs underfoot shift. To remain in play you have to hope that your penguin does not fall off the board. The objective is to stay firmly on the iceberg and return your egg safely to the nest. It is a silly little game and I was surprised when it came to mind.

However upon reflection, “Don’t wake the dragon” seemed a fitting analogy for what the parents’ shared about their experience of first episode psychosis. The “sleeping dragon” is emergent psychosis. There are little inklings that something isn’t right which appears to propel the parents into a protective role. A parent’s hopeful and well meaning maneuvering may serve to leave the dragon sleeping for as long as possible, rendering it powerless to harm the egg. If the parent can reinforce the safety of the nest, the hope is that all will be well with their young adult child and by extension all will be well with the parent.

Bonnie describes how she formerly believed her son was so capable and so confident, that he could do anything he set his mind to. He sailed through his undergraduate degree with very little study and also had success in graduate school. When he began another educational program he moved to another city and everything was going pretty well at the start, but then she became concerned.

> *And ah, I knew there was something different about him, he was acting weird but I thought, oh, you know, he’s just having a hard time. And then he came home once and he said “You hide this piece of paper…. It is the best written material I have ever read, he said, but I don’t want to see it anymore”. It just wasn’t like him. And then he came home to write his thesis because he couldn’t get it done in the allotted time, again you know, not like him. ...I had to keep him to the task. I said okay now get some work done. You know, but I mean he was an adult, you don’t want to tell him what to do, but you know, it was just like he didn’t think he wanted to do it, couldn’t do it, yet I thought he could do it. I tried to help.* (Bonnie)

This passage from Bonnie reflects the concern she holds for her son's success. She is worried enough that she feels it is prudent to bring him back home, back to the safety of the nest, where she could help him, to keep him to the task. His "weirdness" and his inability to keep to the task, elicited a helping response from Bonnie. She tiptoed around her son, trying to orchestrate his "*keeping to the task,*" vehemently intent on not waking the dragon. Certainly, one can hear the loving efforts Bonnie made to protect her son from the dragon. She was trying to protect him from worsening "*weirdness*" and potential failure?

Sharon too, tried not to wake the dragon. Her daughter appeared to be experiencing high levels of anxiety and severe fatigue as she approached the final semester of her undergraduate degree. Mom initially wondered if the birth control pill was causing her daughter to experience a depressed mood and encouraged her daughter to discontinue it. After graduation in the spring, her daughter relocated to another more distant university to take summer courses. Within, a short period of time, Mom received a distress call from her daughter. She had been unable to complete a quiz and risked expulsion from the program. Upon arrival, Sharon noted that her daughter was having trouble concentrating and offered to help.

> *So I said we're gonna book a room in a hotel and it's just gonna be you and I. … I thought the two of us could work through it and I could help her out. So we're in this air-conditioned hotel room and she said she wanted to do it, she never verbalized to me once, that she wanted to quit or come home, she said she wanted to do it, but we went out to eat and she hardly spoke…. in*

> *the back of my mind I knew this was serious but I didn't do anything about it.* (Sharon)

Sharon's help was to remove her daughter from the confines of her non-air conditioned student room to the coolness and order of a hotel room. She then attempted to help her daughter study by helping her "*work it out*". Although Sharon recognized that something was really wrong, she waited for her daughter to say, overtly that she wanted to quit or return home. Sharon essentially over rode her own intuitions in order to protect her daughter from the dragon, acting in concert with her daughter to preserve the possibility of success. Sharon's actions are particularly interesting as she tries to protect her daughter's future possibilities.

Without exception, all the parents tell a story of trying to protect possibilities. The parents are experiencing a novel situation, (first episode psychosis) and based upon their former coping skills, they initially act to "make things right". To smooth out the wrinkles, the perceived to be 'temporary rough patches' in life, parents respond with well-meaning offers of instrumental help. In the earliest moments of awareness, these offers include a change of location, an opportunity for rest or respite, a vacation, help with homework, tutoring, or seeking alternative educational avenues or accommodations, or different vocational pursuits. Protective comfort measures offered by parents include suggestions of a relaxing bath, a glass of wine, a hot beverage, a quiet meal, a drive somewhere, availability of companionship and supportive, encouraging conversation. Parents describe trying to take their lead for what was needed from their young adult child. However, despite considerable concern and actions to relieve distress, their caring actions are seemingly powerless. Eventually the dragon awakes, the “weirdness” escalates and *being in the world* requires an *un-ready-to hand* mode of engagement. As said before, the way that humans are engaged in their world is set up and bounded by what matters to them. “Concerns, or those things that matter to us, set up how we enter a situation, what we see and do not see and how we act” (Benner & Wrubel, 1989). In other words, things that matter to parents show up in their actions and responses to the situation. Most often, parents described this period of chaos as a roller coaster that immediately followed the dragon having awakened.

Riding the roller-coaster

There is something thrilling and magical about a roller coaster. I must admit that even at my advanced age, my youthful days long abandoned, that I love the freeing feeling of a good roller coaster ride. I enjoy climbing in to the small car (the front seat is best), tugging to tighten the seatbelt, and awaiting to be transcended into the clank and clatter of metal wheels on metal rails, moving forward, climbing higher, turning sharply, and descending freely, down and down. It is the thrill of having a front row seat on a runaway train, with the wind blowing through your hair, spiraling ever faster, surging ever forward in an unpredictable manner. I love this free-falling feeling, this sense of being out of control in this undulating car - but only to a certain point. After a few rotations on the track, I begin to feel less thrilled. I experience a heady feeling, slight nausea and despite my momentary pleasure search for the end. I look beyond the rail to the possibility of departure from the tumbling, rumbling of the tracks. As much as I have enjoyed the ride, I am soon ready to depart, to return to the real world with both feet planted firmly on the ground and back to feeling less heady and definitely more in control. I want the turning world to stop in order to regain my composure and my balance.

This off kilter sense of imbalance is what parents experience when psychosis emerges. This sense of their adrenaline pumping and being taken on a rollercoaster ride does not stop. They wish for a time to recuperate, to regroup, to catch their breath, and contemplate a steady state. Sharon recalls this need for reprieve just before her daughter was taken to the emergency room at the hospital.

> *If she had refused to go to the hospital I don't know what I would have done. I was… exhausted, I needed all this stress to end. I thought I was going to go crazy. It was like a roller coaster and I just needed to jump off. It was frightening to see her so out of control. I was … we were all out of control.* (Sharon)

I suspect that the loss of control is something we all like and tolerate for brief periods of time. We move away from our usual, and predictable to embark upon roller coasters, go bunging jumping or some other thrilling experience. This might be the reason why we invent and enjoy amusement rides. There is a temporary notion to the thrill-ride moments and we know it to be a temporary experience from the outset. We will experience and tolerate the two or three minutes of adrenaline pumping and endorphins flowing to increase our feelings of wellbeing. However, imagine this experience, when the swift ride, the undulating ups and downs and the screeching sounds of metal on the bends is ongoing, unrelenting or non stop? The once thrilling turns into an experience of terror - sickened by the loss of control or the inability to find a steady, stable place to land on terra firma. Frank recalls a need for some peace:

> *He was acting like a jerk, and saying horrible things to his mother. I couldn't understand what would make him act like that. He was so hard to live with. I just wanted to run away from all the tension. It was hard to support my wife. I told him to smarten up, to behave himself, but he just got worse. I thought well it must be drugs. I thought, he is on some kind of high. I threatened to kick him out several times. I just wanted a break from him and all the stress. It was a horrible time. My wife and I were at odds. When he finally got stopped by the police…(crying) it was a blessing in disguise. Something had to give*. (Frank)

Parents are searching for, seeking a place to be at home again in their world, with their rubber-soled shoes firmly on the ground, dwelling safely and predictably still, without movement. The invitation of short-lived thrills, are enticing, but to dwell in this state of arousal and heightened vigilance for more than a few moments is unpleasant, stressful, and exhausting. The moments of a son or daughter's emerging psychosis are benignly interesting at first but soon feel like a nightmarish rollercoaster ride. This onset of psychotic illness is like a runaway, unstoppable roller coaster that requires stamina, endurance, persistence and staying power. Caregiving is an all-consuming process, mentally and physically. Victoria recalls not having any time for her self or to rest.

> *I was just going through the motions trying to keep our family afloat. It was impossible to keep …[4s}… to keep things clean and tidy the way I like it. He would do such odd annoying things, (quickly) like spit all over the walls...I sure had to lower my standards and try to get some rest whenever he went out. It wasn't like home anymore. Every stained wall told a story of his coming apart at the seams, us too... I wasn't coping well. I needed a break from him. My husband was lucky, he went out to work. The mess on the walls didn't bother him like it did me.* (Victoria)

One needs to stay alert and be ready to spring into action over unpredictable events. Mostly though, parent caregivers are looking for a secure and safe place, a place where they can feel at home in the world and return to smooth coping.

Facing the dragon

Janet, whose son became very ill while away at University, spoke about confronting the dragon. Upon determining that something was very different with her son, she and her husband got in the car and drove many hours down the Trans Canada highway to check on him. This checking on her son was not an unfamiliar or infrequent activity. In fact, Janet recounts numerous times when she or her husband checked on their son, through telephone calls, emails or text messages. Their son had been the focus of worry and concern for sometime, but this particular evening, Janet describes feeling "*scared*", just having a gut feeling that things were worse. She described it as follows:

> *We wanted to bring him home, and um, so we went there and that was the first time that, he didn't let us go into his room. Um, we got there and, we said we just want to know if you are safe …[8 s]… it was obvious that he was in a lot of distress." At that point, I couldn't even figure it out, or even think about mental illness. I just knew my son was not doing well, and I was afraid that he would kill himself. So, during that time there was a lot of fear. A fear, that if you make one mistake, you can lose your son … [7 s]… So that was horrible … a horrible feeling; an almost paralyzing feeling.* (Janet)

Janet portrays the paralyzing fear she experienced in the moments following her coming to understand that her son was very ill. She depicts a scene of powerlessness. She and her husband stood in the parking lot, wondering how to best make contact with their son. Within these moments, the former focus upon supporting her son's academic success, with tutors and accommodation, quickly twists into preventing a potential suicide. She comes face-to-face with the dragon and experiences a paralyzing fear. She knows that *Being* is always *going toward death* (Heidegger, 1927/1962). "Death is something distinctively impending" (Heidegger, 1927/1962, p. 294) for all beings universally. In understanding that her son could take his own life, she embodies a fearful paralyzing terror. When facing the dragon of unpredictable psychosis, Janet felt unable to make a move. She was unable to move, unable to think beyond the moment for fear of making the wrong move. She feared that the wrong move would lead her son to take his own life. She was intensely motivated in facing what she perceived to be a life or death decision to bring this difficult situation to a safe resolution and to save her son from the possibility of death. But how can one slay the dragon without feeling able to initiate an action plan?

Carol describes the moments that she first faced the dragon as follows:

> *I think it was a week night... So then I said, "Well what's wrong?" She goes. "We have to leave,. G's going to hurt us". She, ah, was looking out the window, and she thought somebody was outside". She kept thinking that somebody was in the house and that somebody was outside and was trying to get us."…. "She freaked me out. I drove her to our friend's house where I thought she would be safe. I was scared. I was fighting tears ... [looking upwards to heaven]…This has been a terrible nightmare.* (Carol)

Carol also describes the intense fear associated with the perplexing moments of facing the dragon. Carol initially acts to try to keep her daughter calm, by taking her to "a safe place," but eventually coming to understand that her daughter's thoughts were not making sense and she even wondered if illicit drug use had caused hallucinations. This realization led to a decision to seek help at the hospital. During our conversation, Carol speaks ever more quickly and urgently when she describes these events. She looks up to the ceiling as if in a prayerful posture. She is shaking her head as she talks to me, her eyes glisten with tears and she appears to be reliving the intensity of a nightmare. Her mood is authentically sad (Conroy & Dobson, 2005). Facing the dragon changed her life world. In facing the dragon, she concludes that there is little that she can do to help her daughter. Resigned to get her daughter professional help, she heads to the hospital.

Hannah's son had been the focus of worry for sometime. He had a history of recreational marijuana use and this was the assumed explanation for his "acting weird" at times. The family sought psychotherapy for him, with the goal of reducing his substance use. Hannah and her husband insisted that the son submit to a drug test. The son dutifully complied with all their requests. The drug screen came back negative; Hannah and her husband, apparently "breathed a sigh of relief." That was, until they received a phone call from him late one evening.

> *He phoned at 10 o'clock that evening, um, he, he said I'm in trouble, he had been pulled over by the police….Ah, so anyways, they charged him with stunt driving, he was driving 167 in a 100. Um, so we went to him and just said, "This is not right what you're doing, we can't live like this any more because things are just out of control?" "So then I phoned the family doctor that next day and I just said "Look this is it, ah, something is really, really wrong. We can't continue to live this way.* (Hannah)

Hannah and her husband were startled by a phone call, which served as a warning that the dragon was truly awake. The police charges were the "thing" that alerted parents to something more concerning. There is also a clear disconnect between the son's mood and energy and that of his parents. It would appear that the experiences of the evening, which began with the late night telephone call raised increased parental concern that there was something significant going on.

Hannah's fear is distinctive in its world-disclosing possibilities. Heidegger claims that fear is always fear of something threatening, some particular thing in the world. Fear always has an object. That is, fear is always fear of something, and for the sake of something, for example, "one fears for their life, or fears about some other possibility" (Heidegger, 1927/1969, p. 141). Hannah faces the dragon and experiences the fear of the possibility of "something very wrong here". This takes her into an unready-to-hand- mode *of being* and serves to organize a visit to the family physician and then later to the emergency room.

Once Upon a Time, There was a Ferocious Dragon

Once upon a time there was a ferocious dragon called Psychosis.
The dragon stood tall. It was covered with thick sharp scales.
Its black eyes glowed with evil, and from its big strong jaws
flowed an incessant stream of foul-smelling brown slime.
It demanded from humankind that one out of every hundred
young people be sent over the abyss to the foot of the mountain
where the dragon psychosis lived.
Sometimes the dragon would devour
these unfortunate souls upon arrival;
sometimes again it would lock them up in the mountain

where they would wither away for months or years.

Everyone feared the ferocious dragon.

The misery inflicted by the dragon was incalculable.

He taunted and terrorized the parents of the youth

whose young lives he stole, but the parents fought a valiant fight. JHW.

Figure 5.1 St. George, by Gustave Moreau [19th cent.] (Public Domain Image)

Dragons are ferocious fire breathing mythical creatures that are universally feared. Psychosis is also feared. Best to keep it sleeping, undisturbed and unacknowledged. After all, as was said previously in Chapter Two, mental illness is not something that is ever welcomed. Generally individuals and their families will want to avoid a diagnosis and hospitalization. All the parents I spoke with knew intuitively that something was not quite right, and they were unanimously vigilant in their efforts to “not wake the dragon”. For most, these efforts served to delay help seeking within the psychiatric community for a few months to several years. That is not to say the parents were avoiding trying to get help.

Most parents recalled numerous efforts to get their young adult help from a variety of counselors. Drug addiction counselors, family therapists, academic or vocational counselors, pastors, psychotherapists and family physicians were variously utilized during the help-seeking as the dragon threatened. It is interesting that psychiatric help was not generally the first course of action. There is no doubt that psychiatric help was seen as the last resort. One certainly suspects, that the terrifying possibility of serious mental illness was a significant factor in the way parents initiated offers of help.

If through cultural and historical understanding of schizophrenogenic parenting, mental illness is understood as coming about through poor or inadequate parenting, then preventing its "showing" may have served to protect the parents from feelings of failure. The actions in response to the sleeping dragon of psychosis appear to have a two-fold purpose. First and foremost to assist the young adult and to make things better, to 'smooth things over' with the dragon and the second is to potentially protect the self-esteem of the parent. For most parents, admitting that one's son or daughter has a mental illness is a direct attack on a parent's ego. Parents take responsibility according to well-entrenched social norms for how their children turn out. This is a particularly interesting finding as delays in treatment are the norm in early psychosis. The reasons for these delays are likely multi-factorial but I certainly have to wonder if some of the delay in seeking early treatment is to avoid the dragon, the diagnosis of stigmatizing illness which has a history of serving up parents as the causal factors in its etiology. Delays in seeking treatment are common in emergent psychosis and are often related to stigma and uncertainty related to the illness symptoms (Fink & Tasman, 1992). Rose (1996) found that family members tend to avoid negative labeling and stereotyping of their mentally ill relative.

Once the dragon is awake, and psychosis comes into the clearing, all parents believed (at least in part) that they were culpable for a delay in treatment. They expressed their sorrow and guilt in a hushed confessional tone that they had missed something, or had not attended closely enough to their observations. It is perhaps no surprise that individuals experiencing a first episode of psychosis are generally late to seek treatment. Despite community education efforts to encourage early treatment that may enhance recovery outcomes, the duration of untreated psychosis (length of time from onset to actual treatment) remains quite lengthy, said to be between eighteen months to two years (McGorry 2005; Birchwood, 2000). One wonders if the stigma of mental illness contributes to the terrorizing meaning it holds for parents and contributes to possible delays in seeking treatment.

In this chapter, I summarized the theme of protection, which was so thoroughly aligned with the parent's caregiving experiences when facing an onset of an emergent psychotic disorder in their young adult child. Parents held themselves to blame for the onset of illness and described in clearly confessional postures that they had missed something or had failed in some respect. They also describe the battle to avoid waking the ferocious dragon. Once awakened the dragon of psychosis brought upon a nightmarish rollercoaster ride. The reality of psychotic illness was beyond frightening. Next in Chapter Six, I elaborate upon the fears associated with the emergent psychosis of a loved one. The theme of stigma and the meaning this held for parent caregivers will be exposed.

CHAPTER SIX

"*Darkness cannot drive out darkness; only light can do that*" Martin Luther King

Wrestling with Stigma

This chapter focuses upon the intense need parent caregivers feel to keep secrets. Generally the illness onset of a young adult with emergent psychosis is not an event shared publically. Rather it is a closely guarded family secret. Both the parent caregivers and the ill young adults fall prey to overwhelming worries about the negative stereotypes and stigma associated with illnesses like schizophrenia or bipolar affective disorder. This stigma holds significant meaning for the parents in particular in light of parenting expectations in our culture and leads to deepening the isolation and loneliness of the caregiving experience.

Hide and Seek

Lori Schiller (1994) is a young woman with schizophrenia from New York State who wrote a book about her recovery journey called "*The Quiet Room*". When crafting this book she asked her parents and her two brothers to each write a chapter depicting their experiences of her illness. Her mother and father both contributed very candid and courageous stories of their memories of the early stage of Lori's illness. When I read the personal accounts as written by Lori's parents, I was struck by the way hiding the truth about their daughter's mental illness was a salient theme within the Schiller family. Lori's mom, Nancy Schiller described the following in her chapter (p. 63).

> For the longest time, I told no one where Lori was. The boys knew, (her sons) of course, but no one else in the family did. I didn't tell my sister, I didn't tell my mother, I didn't tell a soul. Marvin wouldn't let me. (Nancy)

Nancy described how hard it was for her to live with this lie. She felt horrible "To be silent and to be so alone with this problem". Her husband Marvin had sworn her to secrecy and had forbid her to tell anyone.

> I forbid you to tell anyone about this. If we let anyone know about this no one will ever let her forget it. It will put a terrible stigma on her. When she gets out she will have to put this behind her. It will be impossible if people know where she has been. (Marvin)

Lori's dad Marvin was a psychologist. He was very aware of the stigma that surrounds mental illness and saw no value in the disclosure of his daughter's illness to anyone. Nancy was uncomfortable with this at first and raised concern about living a lie but Marvin "wouldn't budge".

> Nancy: How are we going to keep a secret like that? She may be in hospital for a while.
>
> Marvin: I have thought of that. From now on the story is that Lori has gone back to Boston to study. It is a logical thing to have happen.

Nancy goes on to say that the "deception made everything ten time worse for her. She laments "needing to talk, to vent, to get sympathy and support from friends". Instead she could confide in no one and felt very uncomfortable lying to her friends. She "hated pretending everything was all right when it wasn't."

In light of my conversations with parent caregivers I was not surprised by the comments made by Nancy Schiller about the elaborate deception which was being orchestrated by her husband to help their daughter Lori avoid the crippling stigma of mental illness. As parents they had an awareness of the cultural background and social practices that shape the care and treatment of those with mental illness. The treatment of those with mental illness has historically been quite negative and stigmatizing (Lefly, 2000). Iconic movies such as "*The Snake Pit*", "*Girl Interrupted"* or "*One Flew Over the Cuckoo's Nest*" have added to this negative perception. Similarly, the artistic depiction of "Bedlam" the name for the Bethlehem Hospital below in England, provides a notion of inhumane treatment and the substandard warehousing of the insane.

Figure 6.1 Bethlehem Hospital Archives 1867.

Bedlam was a place for disposable people, those who had no useful purpose in society. In fact the residents in Bedlam were considered worthy of ridicule. On Sundays, members of the public would make an outing of travelling to Bethlehem Hospital to catch a glimpse of the insane. No wonder parents even today go to great lengths to keep the mental illness of a loved adult child a secret. Marvin Schiller, in response to his daughter's first suicide attempt shares his views on this crucial moment.

> The important thing was to get Lori the help she needed. I wanted to put the whole thing behind us as quickly as possible. In my mind the most important help she needed was to make sure that nothing of this incident ever came to light. As a psychologist, I knew she could carry a psychiatric label for a long time, if not forever. I didn't want my daughter to be stigmatized by some temporary rash act … but the hospital personnel thought she should stay for a few days in the psychiatric ward for observation. That was out of the question. I didn't want anything on Lori's record to come back and haunt her in her later life (Schiller, 1994, p.41).

Thomas, struggled with the pros and cons of sharing his son's illnes. He too had insisted that his wife stay silent. He shared the following,

> *I am uncomfortable with anyone knowing about this. We have to be very careful to keep our business to ourselves. We can't risk it. I think the world is not ready to talk… like… all out in the open about this kind of illness. People will judge him, and well they will judge us too. My wife*

> *doesn't agree with me, she says we should be more open with people but I just don't think this is the time. No , our son has too much to lose.*

Thomas makes a point of acknowledging his anxiety and worry born out of what he believes is a *world* which is not ready. He describes what he understands to be a social context of silence surrounding mental illness.

Living Like a Turtle

With intuitive concern and later upon confirmation of a tentative diagnosis of mental illness, almost all the caregiving parents with whom I conversed sought solitude, and consciously or unconsciously to hide themselves away from their usual social habits and pursuits. The hiding, like a turtle receding into its shell and pulling inward, is not without its purpose. It seems that this period of isolation is also a concurrent time of seeking. Seeking answers to the salient "What" and "Why" questions. Why him? or Why her? or Why us? What did we do to cause this? What about our other child? Why now? "What should we have done differently? What did we miss? What if anything did our loved one do to invite this illness? Parents try to make sense of this novel personal experience. They hide, shrink pare down the size of their world. They try to remain concealed. They make repetetive effeorts to keep their space small, to conceal events. Yet when they conceal, the opposite appears, and the concealment bring psychosis more fully into view. Whenever we reveal something we cover over something else.

Heidegger made reference to *aletheia* as an *unhiddenness* in relation to that which is hidden (Coltman, 1998). Aletheia occurs when something opens which was once closed. Aletheia can be represented by the metaphor of opening the lid of a well — of flipping the lid open and letting it rest allowing one to look into what lies beneath it. In this opening of one side, another side is closed, for with every opening there is closure and some things are necessarily left behind (Gadamer, 1989).

Sharon describes this time of opening as anxiety provoking and heartbreaking.

> *Once she was admitted, I felt momentary relief because I assumed she was finally in a safe place and could get some help. I was exhausted from all the sleepless nights. I just wanted to sleep but I couldn't settle. I was heartbroken to think of my beautiful young daughter in a place like that. I spent hours at a time trying to review her life and wondered what we had missed. It was a horrible time. My husband and I were really hurting. We were frightened for the future.* (Sharon)

Parents of young adults confronted with the diagnosis of emergent mental illness experience shock, confusion and search for solutions. They also struggle to acknowledge the potential permanence of the illness (Badger, 1994). There is a time of initial reflection and a time of searching for answers that is followed ever so quickly, or for some even simultaneously, by a time of rapidly consuming information about how to make things better, seeking answers to the "How" questions. How do I fix him/her? How do I get the right kind of help? How do I keep this a secret? How do I tell others?

Victoria admits to having read quite a bit about mental illness before her son was finally admitted for treatment. She and her husband had been struggling to get a variety of supports in place to help their son. They tried their best to get him the help he needed, but found that it was very troublesome. Victoria's son was resistant to a mental health assessment. She too, wanted to see an end to the struggles with her son.

> *We tried our best to get some help, but his substance abuse history was a problem. Everyone thought he was addicted to pot, and insisted he be sent to rehab. But even in rehab he was "off the wall". He had all kinds of weird behaviours and had difficulty staying in the um… addiction treatment groups. Now, we know he was paranoid and hearing voices, but back then I thought he was just being deliberately uncooperative. I was annoyed with his silly behaviour. Umm…we were desperate to see an end to our struggles with him. He literally consumed our whole life and our other kids suffered. We never dreamed it was schizophrenia. When we found out we were so shocked. I had read about it but I never dreamed it could happen to my son. At first I couldn't tell anyone. I felt ashamed.* (Victoria)

Thomas notes the pain of the sudden isolation born out of feelings of shame and awareness of the stigma. He also suggests that it is difficult to trust disclosure to others. It impacts the future as well as the present.

> *This stuff, just um, there appears to be so, so much stigma attached to it, and people don't understand what it means. If he had a broken leg he'd be walking around with a cast, and this is how we would get help. But it is not a broken leg. It… it's something with a pretty strong stigma attached to it. And what's going to happen in the future with that, and ah, for example we have not told anybody*. (Thomas)

Thomas is not the exception. Almost all the other parents described this same retreating turtle-like approach to the early months of their caregiving. The hiding served to reduce the gaze of stigma by others and to provide an opportunity to come to personally understand more about the illness and how best to proceed. There is a notion of figuring out how to best put "a spin" on things but also figuring out what might be most helpful in protecting their son or daughter's future possibilities. This was described consistently as a very lonely time. Again, Bonnie puts her feelings of isolation into words.

> *It is so difficult to be so sad and so worried and not talking to anybody. Ooh. It's so lonely because I didn't want to talk to anybody. You couldn't talk to people. Like not even my other kids, I didn't want to talk to anyone.* (Bonnie).

This action towards parent's 'turtle-hood', a withdrawing inward into a hard protective shell and away from others, serves to maintain privacy but it also does not allow others to enter a relationship with them. Living like a turtle, holding a secret, functions to "prevent others from learning intimate information" (van

Manen & Levering, 1996, p. 59) about them or their young adult child. Parents at this early stage of their young adult's mental illness begin to live a secret life. They hide from others and live with *fear* about the stigmatized future.

Heidegger's (1927/1969) discussion of mood helps to explain this *fear*, heightened by the uncertainty of a future perceived within our cultural norms to be restricted. Heidegger breaks fear down into three intertwining parts: What we are afraid of, fearing itself and why we are afraid. What we are afraid of is always something we encounter that has the character of being threatening. However the *mood* of fear itself is the way we discover something threatening. "Like all moods, fearing is inseparable from the understanding and it is the means by which a world opens up to *Dasein*" (Elkholy, 2008, p.202). As a mode of comportment, the *fear* of stigma allows what is threatening to approach the parents in their lived situation. *Fearing and what is feared is inseparable*, (Heidegger) for it is fear that brings about that which threatens parent caregivers. The parents with whom I spoke certainly held some fear for themselves but were more often concerned for and held stronger fear for their young adult child. In fearing, Dasein is "left to itself" (Heidegger, 1927/1969, p. 141). One can also have fear for another. In fearing for another, one need not be in the mood of fear one self (Elkholy, 2008). In sharing the world with others, one comports to another's world by understanding the others' mood. The fear of disclosure and threat of stigmatization is a pervasive fear among parent caregivers (Chang & Horrocks, 2006)

Abandoned by Others and Alone

Carole expressed anger towards her daughter's friends. They had all but abandoned her. Carole noted that it was like her daughter had "dropped off the face of the earth".

> *It was the strangest thing. When she came home from the hospital no one bothered with her. It was like she had dropped off the face of the earth. I know that her friends knew she had been in the hospital but they never came to visit. A couple of them left messages on her cell phone but they did not reach out in person. It was horrible to see her so ill and so alone. I think they were afraid of her*. (Carole)

Dropping off the earth is an interesting way to express the feeling of strangeness and distance in the way others treated Carole's daughter. Carole certainly expected more from these friends. Following her son's depressive episode, another mother, Bonnie expected far more from her own friends.

> *You know, I had asked for prayer for him. My friends at church knew he had been depressed. I didn't tell them he was in hospital but I had shared with them that he was having a hard time. They would see me at church and it was obvious that he wasn't there, but no one asked about him. (Shaking her head) Well it was like a big elephant sitting in the room that no one wanted to talk about. I felt so hurt. It was horrible to feel so alone. I was heartbroken. I expected more from my friends at church. I think I expected more from them as Christians*. (Bonnie)

I think it is a rather universal notion that when one is going through a rough patch in life to enjoy getting support from others. One common form of support is in the form of greeting cards that relay notions of thinking of you or get well wishes. Alternately friends might send flowers, helium filled balloons, and cuddly stuffed animals or my new favorite the chocolate dipped edible bouquet, accompanied by words of support and encouragement. But when your son or daughter develops mental illness there is an absence of acknowledgement. It is indeed a very lonely time, made even lonelier and isolating by the absence of support from others. They close down spaces due to guilt and shame. Life goes into a holding pattern of sorts and parents find themselves even more alone.

> *I can't talk about this stuff. I think it is better to keep it quiet anyway. It isn't easy to just come out and say, "My son had a breakdown and he is sick". People don't understand. I think they can see he is different but we don't talk about it. It is different when it is a broken leg or something.* (Frank)

For some parents like Frank, the absence of support is due to keeping secrets because of the perceived need to conceal the onset of mental illness from others, even close family members. Although some parents chose to share their concerns about a son or daughter, others are uncomfortable and uncertain as to how to respond and reach out. The stigma of a serious mental illness brings social discomfort and interpersonal distancing, further fueling feelings of parents' isolation and difference.

A Secret Life

> *I wished I could of said something. There I was, um, trying to work and concentrate when all I could think about was my daughter in the hospital. I was a mess. You know, … I knew I wasn't doing a good job at work and I just wanted to yell … Give me a break guys, don't you know what I'm going through. But I didn't say anything. Then it got so bad I had to take time off. I just told my boss my daughter was sick. I didn't elaborate. I think some people guessed but no one really knew for sure*. (Sharon)

The emergent mental illness of a family member invites isolation and the potential for social rejection, either invoked deliberately or unintentionally. No one sends cards or flowers. Most people try to remain distant, ignoring the events, while diverting their eyes to look elsewhere. The phone stops ringing and isolation mounts. A secret life evolves because one quickly gets the message that this is a transforming event that will alter perceptions of credibility and competence. For the parents of those with emergent psychosis, secret keeping becomes the new norm. The onset of mental illness and the labeling of a psychotic disorder in particular, transforms the identity of the one who experiences the symptoms as well as to close family members. There is stigma, and discrimination that surrounds the events of emergent psychosis and simultaneously engulfs the individual and his or her parents into a deeply isolating web of silence. It is a sorrow-filled time exacerbated by the most intense feelings of shame and failure. It means being an outsider, a stigmatized "non normal" who no longer warrants cards or flowers. Hannah cried and sobbed for quite sometime after she disclosed the following to me.

> *We are so alone with our heartbreak and worry. It is a nightmare and very, very lonely …[sobbing and crying] … It is a heartbreak …[9 s]…that's for sure.* (Hannah).

Hannah was one of the participants who I asked repetitively if she wanted to take a break or discontinue the conversation. However in response, she insisted that it was a good thing and provided a sense of relief to finally have the opportunity to share this heartbreak with someone. (I write more about this need to share in a safe place in a subsequent chapter). She went on to explain that much of her life since her son became ill has been kept a secret. It was also clearly a point of disagreement between her and her husband as she describes below.

> *He said "don't tell anybody, um, because people don't understand" and in some ways that is true so we have hardly told anybody. And it's not because I'm ashamed, because I'm not, um, but that's been the hard part. It's just, um, nobody really knows. And I'm not sure if that was the wisest decision. My husband really felt strongly about it. Um, because he wanted to protect our son, because he said the problem is, when you tell people, they tell people, and they tell people, and he didn't want our son to be judged.* (Hannah)

The harsh reality of potentially negative judgment of a loved young adult child motivates the secret keeping. Such secret keeping appears to have a dual purpose: one to preserve the loved ones reputation and credibility; but secondly to protect the parents from experiencing more guilt and shame and stigma by association. At this early stage of illness onset the parents are still trying to seek answers to those pressing questions about guilt and blame. Once some of these answers come to light they may feel less protective of this secret but early in the caregiver journey silence reigns. Silence provides at least the illusion of privacy and the hope to prevent any further stigmatization or spoiled identity (Goffman, 1963). The following is a poem I wrote to highlight the dilemma of secrecy experienced by parent caregivers in response to the onset of mental illness of their young adult children depicting the power of the faceless enemy of stigma.

My Lips are Sealed

Hush, shush
Don’t tell.
Stigma surrounds
Turning inward
Thoughts Racing
But none to voice
TELL?
No, don’t tell.
Keep hushed
Secret life
Faceless enemy
Wins.
(JHW)

Stigma is a deeply rooted prejudice that despite many costly community education campaigns continues to hurt those who experience serious mental illness and their loved ones. Mental illnesses represent unique experiences for parents in no small part because of the enduring social and cultural climates of secrecy, stigma and a tendency to characterized individuals with mental illness as weak, dangerous or unpredictable (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000). Within our culture it is not considered safe to disclose that a relative is mentally ill. It is perceived to be a risky venture with potentially serious social consequences. Sadly stigma is recreated each time we stereotype those with mental illness. Thomas puts it this way.

> *It is like people look at us differently. Like we are not a normal family anymore. Somehow his illness has made us all suspect. We have four other perfectly normal children but aw…that doesn't seem to matter. When our son is out with us and.. aw.. and he .. aw.. is acting or looking a little bit , you know,…[3s]…different, other people shy away. I can see them talking about him, ridiculing him. People think its funny. They don't understand.* (Thomas)

Thomas feels angry that his son is treated as an object, ridiculed and looked at differently. Thomas feels the pain of this stigma and can hardly contain the anger he feels toward those who treat his son in such an unkind way. Although he recognizes that this behaviour is the result of not understanding, he certainly does not agree with this ignorance. However, neither is he prepared to disclose his son's illness to others. It is a difficult balancing act. Disclosure could alleviate the ridicule and bring with it greater understanding but disclosure of the secret is also threatening. The secret life continues.

Sticks and Stones

> ‘Sticks and stones will break my bones but names will never hurt me’… Psycho, loonie, retard, crazy, whacko, nut, mental, barmy, bats in the belfry, batty, berserk, bonkers, cracked, crazed, cuckoo, daft, delirious, demented, deranged, erratic, flaky, flipped, flipped out, freaked out, fruity, insane, kooky, lunatic, mad, maniacal, nuts, nutty, nutty as fruitcake, of unsound mind, out of one's mind, out of one's tree, out to lunch, potty, round the bend, schizo, screw loose, screwball, screwy, touched, unbalanced, unglued, unhinged, unzipped, wacky.

I remember this little singsong chant from my childhood and I also remember teaching it to my daughters when they were school-aged. I am pretty sure I learned it from my own dear mother. It seems to be a “truism” that we teach our children in response to them being called unkind names. However, upon reflection, I now wonder about the unthinking wisdom of this statement and more importantly its meaning. It suggests that a physical attack may cause injury but a verbal attack cannot hurt. I think not. If you called me any of these names it would indeed hurt me. It would indeed wound me. If you called me these names often enough it would most likely break my spirit, undermine my sense of value and would frankly motivate me to withdraw. These names do hurt. Healing from broken bones is rather quick and predictable. Healing from hateful and repetitive verbal insults is infinitely more difficult. Is it any wonder that individuals labeled with mental illness and their families keep it a closely guarded secret? A closely guarded secret it is. Sometimes the secret is even guarded from other family members. Having a young adult child with psychotic illness brings concerns about stigma and fears of rejection due to stereotypes about aggression, violence, and harm. Frank courageously raised this point.

> *I think there are lots of people who associate mental illness with violence. I know I did before our son got sick. All I knew was from movies or stories in the paper. Remember John Hinckley Junior? He tried to shoot Regan, remember? Well that is the kind of thing people think about when it comes to mental illness. That is why I don't say anything. People have the wrong idea about these things.* (Frank)

Frank is right. These negative stereotypes are reinforced frequently in movies and in fictional portrayals of those with mental illness. Additionally, every so often an individual with mental illness does something that evokes the attention of the media. These desperately sad stories sell newspapers and fuel the public's gruesome appetite for sensationalist news coverage. Before you know it there is a network TV news van parked outside the family home of the accused. Just this past year during the time I was writing this thesis, Jared Laughner's shooting of Gabrielle Giffords, the US congresswoman and others at an Arizona mall took center stage. Soon after the shooting, his parents were filmed by news photographers as if they were complicit accomplices. The message sent out from the media was clear: they (Jared's parents) should have stopped this murderous rampage.

Frank's own memory of the violence of the mentally ill arose from the well-known case of John Hinckley Jr. This led to me seeking out and reading the book "*Breaking Points"* that his parents, Jack and Jo Ann Hinckley (1984) wrote about their experiences following the very high profile shooting of President Reagan and his press secretary, James Brady. John Hinckley Jr.'s parents described the frightening weeks following the shootings in vivid detail. They were in effect held captive by the media. They were in shock about what their son had done and had absolutely no idea that he was planning such a thing. They certainly knew he was struggling to find his way forward in his career path during his early adult years but they did not understand that he was mentally ill and experiencing delusions about John Lennon and Jody Foster. His potential for violence was the last thing John's parents worried about. John was a very shy man, isolated and with few friends. His dad Jack describes finding out details about his son John Jr. from the newspapers.

> According to the papers, John's attraction to Jodie Foster came about through seeing her in a film called "Taxi Driver." It was a violent story, from the accounts, in which the movie's hero stalks a presidential candidate with a gun in order to get a girlfriend's attention. But --- that was make-believe, a story on celluloid. John knew the difference between fiction and real life… Didn't he? (Hinckley & Hinckley, 1985. p.170)

Feeling trapped by all the news media and unable to escape their critical gaze, Jack and Jo Ann Hinckley withdrew. Their house became their "hideaway." They were vilified daily by the press. It was said that they had raised a monster.

> Whatever the bafflement, whatever the ugliness, you do not stop loving your child. But somehow love had not been enough. Not the tough love I thought was needed or the tender love Jo Ann gave. Both of us had been reacting to behaviour, never suspecting that behind what we could observe, a tortured private scenario was unfolding. What could have lifted the curtain for us? (Hinckley & Hinckley, 1985. p. 172)

Not only were Jack and Jo Ann astonished by their son's actions. They were accused of having a role in his actions. Through receipt of letters from the public, the Hinckley's were taken to task for loosing a monster on society (Hinckley & Hinckley, 1985). "You should have known he was a killer when he bought so many guns. Others reproached us for our supposed wealth" (p. 174). Being blamed for loosing a monster on society is good enough reason to stay silent.

In 2009 there was another sensational story involving Canadian Vince Weiguang Li, who while floridly psychotic, and off his prescribed treatment medications, slay a young Winnipeg father on a Greyhound bus. The details of both of these tragic events very quickly found the media reporters pointing accusatory fingers toward the family. "Where was the family?" asks Joe Public. "How could the family not prevent such a thing?" " How could they not know?" Of course all of the details seem so clear from the perspective of hindsight but when one is in the midst of these events it is not so easy to determine risk to self or others. Even trained clinicians and highly skilled forensic professionals have rather limited success in accurately determining dangerousness (Monahan, 1974).

It is to most of us, and certainly to the parents I met, the unspeakable, the unfathomable, and the most unlikely possibility. Sharon describes a transformation in her formerly gentle daughter.

> *She is usually a gentle person. But when she was manic …. Oh wow ..she was so different. It was peculiar to see her running around and so irritable. It was hard to know what to say. Every time I tried to get her to settle down, to just, she…. she would accuse me of standing in her way. Um…She said I didn't want her to succeed. She said I had no faith in her. Seriously though, I was afraid for her. She was doing things that were so risky and was out of control. Really…. honestly,.. I felt a bit afraid of her.* (Sharon)

I suspect it would take considerable effort and imagination for any parent to even consider the notion that a child that they love and care about would be capable of any crime, let alone violence towards another person. The parents I met did not consider their young adult child to be dangerous, let alone a potentially murderous criminal. Rather, simply a loved one experiencing symptoms of a distressing mental illness. If anything, more often than not, parents were concerned that their young adult child would harm themselves. However, the public perception and fiercely held cultural stereotypes of dangerousness loom heavily upon the minds of parents. All of the parents I had conversations with were able to share their highly stereotyped versions of what they thought schizophrenia or bipolar disorder was before their son or daughter became ill. They all had erroneous notions of possible "institutionalization", assumptions of “hopeless cases”, “homelessness”, “unpredictable psychos,” “extreme vulnerability to stress” and “violent persons”. These depictions stemmed from movie characters they had seen portraying aspects of mental illness. Even those that personally knew someone else with mental illness were still influenced by thoughts of chronicity, personality change and violent unpredictable outbursts. Fear of the ugly transformation in their own loved ones was a consistent concern expressed by most parents. They struggled with wanting to be hopeful about the future but also felt as was so clearly suggested by parent caregiver Frank, “We had best keep the lid on this, no one needs to know about his illness”. Parent caregivers believed that minimal disclosure and secrecy would more likely bring about eventual social and vocational acceptance for their young adults. The secret keeping appeared to be connected with leaving open possibilities for the future. Heidegger (1927/1962) reminds us that the world is always a world of “*withness*,” we human beings exist with others, and that being-with is an aspect of our being-in-the-world.

> This being-there-too with them does not have the ontological character of being objectively present “with” them within a world. The “with” is of the character of Da-sein, the “also” means the sameness of being as circumspect, heedful being-in-the-world. “With” and “also” are to be understood existentially, not categorically. On the basis of this like-with being- in-the-world, the world is always already the one that I share with the others. The world of Da-sein is a with-world. Being in is being-with others.

> The innerworldly being- in- itself of others is Mitda-sein.
> (Heidegger, 1927/1969, pp. 111-112)

As Heidegger suggests we have understanding because we are always already in the familiar understanding of our cultures and our society. We are not disengaged from others in our practices, but dialogical beings engaged in our world through a shared community of understanding that is for the most part unarticulated (Taylor, 1991). Moreover, parent caregivers were acutely aware of what 'Joe Public' thinks about those with a diagnosis of psychotic disorder. As such, parents despite their isolation and loneliness, selected to keep secrets. Bonnie clearly described the reason she kept silent.

> *Because they will talk, right, to other people, you know, did you hear about so and so, he's got ...[9 s].. [uses her right hand and makes a circular motion pointing to her brain]...And then right away they will think less of you too. You know, they look down on those people.* (Bonnie)

For Bonnie, keeping the secret was an attempt to preserve the former identity of a loved one and to prevent rejection or a perception of her son's diminished credibility. She also suggests that when one in the family has mental illness, all members of the family are treated with suspicion. When a youth with psychotic disorder acts in ways deemed odd or at odds with social norms, it is felt to reflect upon all family members. Bonnie's comment also tells us something else. She uses the descriptor "those people" to describe individuals with mental illness and sets up the cultural norm of 'us' versus 'them' and I suspect unwittingly objectifies and dehumanizes those 'Others' with mental illness.

Mental illness spoils an identity. In Goffman's (1963) theory of social stigma, stigma is defined as an attribute, behaviour, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal person. As Merleau-Ponty (1992) writes, the other's gaze transforms me into an object if I am observed as an insect. The objectification of the other's gaze is felt as unbearable because it takes the place of possible dialogue. Bonnie fully understands the consequences of her son being different. She fears that he will be unceremoniously reduced from a whole and usual person to a tainted, and discounted one. What do parents do with this information? Do they share it, or keep it to themselves? The information, when kept to oneself, is a secret, and something to remain a secret. Heidegger was concerned about the consequences of holding secrets. Heidegger (1953/1996) refers to the danger in the covering up of phenomena.

> There are various ways phenomena can be covered up. In the first place, a phenomenon can be covered up in the sense that it is still completely undiscovered. There is neither knowledge nor lack of knowledge about it. In the second place, a phenomenon can be buried over. This means it was once discovered but then got covered up again. This covering up can be total, but more commonly, what was once discovered may still be visible, though only a semblance. However, where there is semblance there is "being." This kind of covering up, "distortion," is the most frequent and

> the most dangerous kind because here the possibilities of being deceived and misled are especially pernicious. (p. 32)

Is all this secrecy still necessary?

As a mental health nurse and the wife of a gentleman with serious mental illness I can certainly understand this reluctance. Even though my husband has had a wonderful recovery and continues to be a model of health and relative mental stability, we both keep his illness a secret in certain situations. Although our personal friends and our extended family all know about his illness, and we frequently speak publically about mental illness, his employer is not privy to this information. I have felt ambivalent about living this double life at times, but my husband feels adamant that disclosure would jeopardize his career. He says" Do you really think the company would trust me with these multi-million dollar accounts if they knew about my illness?" I would like to be able to say, "It shouldn't matter, it won't matter", but that would be extremely naive. In fact in my clinical experience in working with many individuals with mental illness I know that some of them were fired or at minimum made to feel so unwelcome in the workplace that they quit. Mental illness corrodes notions of trustworthiness and credibility. It is a woeful truism in our culture. Being "out" with a disclosure of mental illness is not always better.

The consequences of disclosure have been the topic of some empirical research. In general selective disclosure or "selectively coming out of the closet optimizes social support and limits stigmatization" (Bos, Kanner, Muris, Janssen

& Mayer, 2009, p. 509). Indeed, perceived stigma has a detrimental effect on the self-esteem of those who are open about their mental disorder. Consequently what parents understand about mental illness stigma impacts their disclosure practices and in large part that of their young adult child.

Heidegger (1927/1996) would challenge that position and say that to be authentic, one must struggle against social norm in the world and that we must encounter the world in our own way to be authentic. Heidegger calls this idea of basing one's self on the beliefs of others or the social norm "*falling prey.*" The result of falling prey is a sense of '*lostness*', lost in terms of letting others determine how one is to *be-in-the-world*, letting the "*they*" decide how one is to be rather that the self. When we have fallen prey, we still have a self but that self is a *they-self* rather than being one-self. Human beings have the propensity to choose our own way to be. Heidegger notes that human beings must take responsibility for being aware of the potential to be taken over by the *they-self.* To live authentically is to return the *one self*. "Dasein is the being which I myself always am. *Mineness* belongs to existing Dasein as the condition of the possibility of authenticity and inauthenticity" (Heidegger, p. 49). So for parent caregivers and their young adults with first episode psychosis they are mindful that there is a price to pay for authenticity and they select to keep the illness episode a secret.

Hiding from It

The initial reaction to the onset of mental illness in a young adult child is seemingly the commencement of a complicated, lengthy and involved game of

"Hide and Seek". I remember loving this game as a child. We often organized a large group of us to play after dinner. It was so exciting that I would race through dinner, not to miss a moment of it. To me it was all about strategy, finding that perfect secret hiding place that would assure me safety from being "it". One had to have several good hiding places in mind and be flexible about where to hide to avoid capture. It was a heart pounding adrenalin-enhanced joy when "it" passed right by but failed to find you. The best spots to hide were the ones no one else had thought of within site of the "home," but not in the minds of those chosen to be "it". Hiding then was a fun experience, made all the more fun if you were not captured and never had to be "it".

When I imagine that now, *Being-in-the world* as an "it," brings very different thoughts. With my current understanding of Heideggerian philosophy and feeling much more attuned to how *Being* can be expressed in life, the meaning of what it means to be- in-the-world, "it" has very different connotations. Certainly no one wants to be an "it" and no one wants to be the parent of an "it". An "it" lacks human understanding and is an outsider from the start. It conjures up notions of a stranger, someone living in the margins, and someone who does not belong. The identity of "it" redefines the self as the different 'Other' (Macmurray, 1957). Every action, according to Macmurray (p. 168), no matter how minimal, "is informed and directed by an awareness of the Other-than-self as Other". Frank believes his son's disclosure left him vulnerable to rejection. To being treated as a "different Other." Any perceived 'Otherness' can impact dialogical relationships. Silence prevails.

> *He made a mistake and told his buddies at school about being in the hospital. I think they had noticed him being sort of strange before, but they still included him when they went to the pub. After his hospitalization they didn't call him anymore. He was always hanging around with us.* (Frank)

Celebrating the silent heroes

Sadly those who have had the most robust recovery from mental illness are not recognized for their heroic battle to overcome the day-to-day difficulties because the battle is waged in private and most often remains a closely guarded secret. If only we could give these heroic individuals their due. Although there have been a few brave folks and some celebrities who have "come out", it is interesting that their disclosures have followed their social acceptance, success and/or celebrity. They first made their mark, forged successful careers and once having garnered public affection and/or adoration, "came out". Although I admire individuals like Clara Hughes for disclosing her struggles with depression, and her public education and advocacy work with Bell Canada in February 2011 and 2012, she had little to lose in the struggle for credibility. In fact, it seems she was on the receiving end of elevated personal status for having been successful despite her illness. We embrace celebrities with mental illness. There is a long list of past and present examples of those with mental illness who have "won the battle" like Winston Churchill, Tyler Perry, Margaret Trudeau, Sylvia Plath, Patty Duke, Winona Ryder, James Taylor and Kathryn Zeta Jones. The list goes on. However, for the average non-famous person, whose credibility is not globally established, there remains a gnawing fear of disclosure.

Silence reigns. The result is that average everyday non-celebrities with successful recovery stories, remain the silent majority. Their stories are not generally heard. Stories of trying different medications, overcoming side effects, slowly getting well and finding the motivation to carry on, despite mental illness are almost never articulated for the public. The stories of the silent majority embody the trials and successes that we do not hear about. The more visible minority of individuals with serious mental illness, end up on the streets of our big cities and become our culturally shared perception of those with serious mental illness. For those who suffer from invisible mental illness, which accounts for a very high number of people, selective disclosure is a precarious balancing act (Bos et al.). Should they keep silent to secure protective safety from negative stigmas or should they stand proud and be counted as successes of psychiatric treatment? We tend to only see and therefore count those with the poorest recovery outcomes and forget that those with more favourable recovery outcomes are the silent majority. It has to be an individual decision and one that carefully weighs the pros and cons of disclosure, but continued silence certainly serves to reinforce the common stereotype that those with mental illness have a downwardly spiraling course of illness.

All the parents I spoke with, even though their young adult children were recovering quite well, found psychological safety in keeping the secret. Several of the parents actually coached their children to also keep their illness a secret.

Thomas describes his own reaction after his son told friends about his episode of illness.

> *He tipped his hand. I certainly warned him not to, but, heh, it's his choice, he did. And ah, so I'm sure people, they were a little standoffish to him, so I think, I, …[8s]…He won't come outright and tell me everything but I, I'm sure he found it difficult at times, especially at school.* (Thomas)

Thomas' comments were typical of many of the other parent caregivers who felt it better to keep the illness a secret to protect their young adult children from social rejection. Disclosure is assumed to lead to others being 'standoffish' and rejecting. However it creates a self-inflicted isolation born out of one's understanding of stigma within our culture. Heidegger would say that *Dasein* does things because they have significance and value.

> Dasein finds itself primarily and constantly in things because, tending them, distressed by them, it always in some way or other rests in things. Each one of us is what he pursues and cares for. In everyday terms we understand ourselves and our existence by way of the activities we pursue and the things we take care of. (Heidegger, 1975, p. 158)

When "things show up as mattering to Dasein as threatening, or attractive, or stubborn or useful and so forth" (Dreyfus, 1987,p. 264) then this mattering is the basis for more reflection and evaluating. For parent caregivers their activity is directed in a transparent *taken-for-granted* way towards the future, the *for-the-sake-of*. 'Parents keeping the secret' is the caring practice deemed appropriate to protect the future possibilities of a young adult child with mental illness in the *world. World* is the meaningful set of relationships, practices and language that we have by being born into a culture. “World” as Heidegger (1927/1969) says “comes not afterward but beforehand, in the strict sense of the word” (p. 165).

When someone else ‘comes out’

During the time period that I was initially having conversations with parents during the spring and summer of 2010, there was a wonderful public event sponsored by a hospital foundation in southern Ontario. The event was actually a fundraiser for a mental health program and featured as guest speaker a young woman who had overcome the difficulty of her psychotic disorder and in effect had achieved an excellent recovery. She was a former client of a specialized early intervention program and spoke eloquently about her ongoing treatment and recovery. This event was reported in the local newspaper too. Several of the parents with whom I had conversations had been in the audience that evening and spoke spontaneously about how wonderful it was to hear her speak. The young woman’s personal testimony gave the parents significant hope and affirmed the notion that their own sons or daughters could overcome psychotic illness. They described her as so brave in the way she told her story of recovery, but also noted how courageous it was to disclose her experiences publically. Bonnie had a conversation with her son about the evening and summarized it this way,

> *And so she went open, cause, there was a write up in the paper too for everybody to see. So I told my son about that and showed him the article*

> *and said you know, she's very brave, she obviously wants to do good with her situation. He says, "Maybe that's what I should do, is tell people". I said "Well you have a wonderful job and maybe you don't want to do that at this point because it might put you in jeopardy, right? Cause everybody doesn't understand* (Bonnie).

When someone else has the courage to come out, it inspires others. It provided a real life human example of recovery that creates a hopeful picture for those at a beginning stage of recovery. This self-disclosing young woman provided hope and inspiration for the parents who attended this event. She held hero status in their eyes. Despite this however, parents continued to coach their own sons and daughters to remain silent, especially to preserve employment status. Victoria also attended the event; she said,

> *I think that she (the speaker) was amazing, she was so inspiring but it is really a puzzle to me, like yeah, some people go right open and tell everybody, and other people don't. I don't know what is best. I just don't know. I think an employer would frown on this or treat you differently if they knew.* (Victoria)

Public images of those with mental illness are generally very negative. Certainly the media continue to portray those with mental illness as deviant, dangerous and less competent (Wahl & Harmon, 1989). Stigma has a tremendous impact on the daily lives of people with mental illness. For instance social stigma contributes to low income or unemployment among the mental ill (Markowitz, 1998). Furthermore those with mental illness often report a reduction of social supports following diagnosis (Feldman & Crandall, 2007). In addition, the family often suffer stigma by association. A concealable stigma, like that with most mental illnesses, then, brings about important reflection upon disclosure decisions. Considering the pros and cons of disclosure weighs on parents. There is no clear answer and depends so much upon the perceived consequences of "coming out". For the parents with whom I spoke , silence was the predominate practice. However, one mom, Janet, following several months of research and intensive self study on her own, began to selectively disclose and described this as "a relief". This would be considered a paradigm shift, where her world began to feel safer or somehow less threatening overtime. Overtime she felt more comfortable selectively sharing news about her son's mental illness with her family and closest friends.

Worse than cancer

Is anything worse than cancer? Cancer is a dreaded disease which brings with it notions of almost certain death. For me, as a person who lost both my parents to cancer and has accompanied my older sister through two dreadful bouts of breast cancer surgery and reconstructive treatments, I was quite dismayed to hear several parent caregivers in my study suggest that it would be easier if their son or daughter had cancer. Easier how, I wondered? I was honestly shocked at the revelation that cancer with its often times, grave prognosis would be a preferred illness to psychosis.

One dad, Harold said this several times within our conversation and asserted that the catastrophic aspects of psychotic illness were much more distressing than a diagnosis of cancer. "*No one blames a parent if their kid gets cancer, but when your kid goes crazy, it is always the parents to blame".* Sharon said it this way: "*I know it sounds terrible but I wish she had cancer, then everyone would be supportive and I would feel less shame"*. The meaning of the emergent psychotic illness to the parents was a sense of resounding shame and failure. Parent's guilty notions of failure to somehow protect their young adult children against mental illness were ostensibly constant companions. Parents all believed that they must have had something to do with the onset of illness. They attributed causality to their failure in some aspect of parenting. Psychosis of their young adult child was somehow perceived as a punishing outcome for a non-descript most often unarticulated parental failure. They too, experienced stigma by virtue of being the parent of one with mental illness. Goffman (1963) called this courtesy stigma (a stigma acquired as a result of being related to a person with a stigma).

The notion that a diagnosis of cancer would be preferable to that of a psychotic disorder is still a stunning revelation to me. However, I think I can understand a little more now. No one holds the families of those who have cancer responsible. That is the sad reality. Despite all kinds of scientific research about causal notions of mental illness, the lay conception continues to assign blame to families. Victoria, whose son had struggled for several years with psychosis and concurrent substance abuse, provided this insight.

> *Um, you just feel for them, like I, I feel sorry for him, because I think, you know, he's going to have to live with this for the rest of his life and so am I. I mean it's not quite a terrible thing like cancer or certain other illnesses, but I think it's just as hard, or even harder because of the stigma and everything attached to it as well. It is a battle everyday*. (Victoria)

The stigma and associated courtesy stigma experienced by parents was so substantial that many of the parent caregivers considered a diagnosis of cancer a lesser one, certainly a less lonely, less rejecting and stigmatizing one. I am mindful that having a relative with mental illness can be a lonely experience. It is an experience that others, friends, family and co-workers are ill prepared to respond. We do not have many opportunities to role model or practice this behavior. So mental illness stays a shameful and well-kept secret. We do not respond with finesse to shameful secrets. We turn away. Generally we ignore what we know on an intuitive level to be an uncomfortable and painful experience for families in a half-hearted attempt to pretend we don't see it. Martin Schiller, author Lori Schiller's dad, who we heard from earlier in this chapter, "wouldn't budge" initially and forbid his wife to discus Lori's illness with anyone. However, after some time he relented and began to inform close friends. He described the following.

> We tried to explain that we had concealed it (the truth) for Lori's sake, hoping to shield her from the stigma. People were polite and seemed concerned. Their expressions were sympathetic but we could see they were

> shocked. We were surprised too. People didn't behave the way we had expected them too. Some of our closest friends had the hardest time with the news. Very few people ever asked about her and even fewer ever visited… Deep down our friends were probably afraid of Lori, afraid of what she might do. (Schiller, 1994, p. 119)

I see this daily in my clinical practice when someone with mental illness acts in a way that is unusual or bizarre. In order not to draw attention to this behavior and potentially bring upon potential awkwardness, others ignore the action. They turn away and hope that in the absence of a face-to-face witness, the person who is acting strangely will experience less pain and humiliation. The person we are is a being capable of love and deep feeling, seeking human warmth and the presence of others. The human person is a relational being. These aspects always remain whether the person is healthy or sick (Lavoie, Dekonick, Blondeau, 2006) but when face to face with those with mental illness and their caregivers we seem less capable of care. According to Levinas (1985), "to take care of the other is a moral obligation, a responsibility impossible to circumvent and arises from the fundamental call of the human face". The human face obliges each and every one of us, leaving no possibility "to remain deaf to its appeal" (Levinas, 1972 p. 49). Perhaps we need to orchestrate more face-to-face opportunities for those with mental illness and their families to become our responsibility.

Opening the closet door just a crack

I am struck by the number of times that parent caregivers described a process of moving inward immediately after their ill son or daughter was diagnosed with psychotic illness. The unfolding recognition that the struggles of their young adult children were related to mental illness, as opposed to other seemingly less stigmatizing possibilities, appeared to be a strong catalyst for withdrawal from usual social life. In a time when those who are marginalized from the mainstream, are often encouraged to take a stand and come out to be counted, there is no such invitation for those with mental illness and by association their families. They do not feel safe to “be out” with this information.

The sense of wrong doing also invited further notions of parents’ stigma. Not only did the young adult and his or her parents have to deal with the reality of a potentially serious mental illness, they also had to cope with the resulting assault on their identity and self-esteem. Patricia Deegan (1996) calls the label of illness a ‘package plan’. The ill person and their families must cope with issues of recovery, but they must also prevent the potential for marginalization, stigmatization and second-class citizenship. The *world* is essentially not a welcoming place for those who are different (Goffman, 1963).

This chapter summarizes the story of stigma. It provides a showing of the extent to which stigma has an impact upon the experiences of parent caregivers and their young adult children with psychosis. In fact stigma has a staggering impact upon parent caregivers of those with first episode psychosis. It evokes fears about the present and the future and makes the early stage caregiving experiences a very isolating and lonely journey. The next chapter will describe the third overarching story of loss.

CHAPTER SEVEN

Nothing in life has meaning except the meaning we choose to give it….Shakespeare

Shattered Dreams: Holding Hope

I summarize the third story that was ever-present in the conversations with parent caregivers. There were many stories of sadness about illness having transformed their young adult's lives and even more suffering and unhappiness when parents shared their thoughts about the potential impact that illness might have upon their son's or daughter's future life and possibilities. I also explore the notion of sorrow experienced by the parent caregivers. Finally, this chapter describes parent's stepping carefully over slippery stones as they seek a comfortable balance vacillating between suffering and hope.

Snatched

More often than not, parents expressed frustration in the face of the nondescript, unseen, intangible and most often the unspeakable "it," (referring to the psychotic illness) that changed their son or daughter. The way that they recalled the insidious onset of illness was akin to some alien force having slowly kidnapped or "snatched" their son or daughter and irreparably altered them. Parents were generally unsettled by unfolding events and tried everything of which they could think to hold tight to their loved ones. Janet described it as a perplexing time.

> *I wasn't sure what to think. It was all very perplexing. Some days things seemed sort of OK, like he was on an even keel and I would feel more relaxed. But then a few days later he would be irritable, swearing and saying hurtful things to me. He wasn't the same person. He was out of control and not himself.* (Janet)

Victoria described the changes in her son as a slow transformation.

> *It was horrible to witness the slow transformation in him. He was so different. It became almost… impossible to live with him. He was up all night and we couldn't sleep. He would take off whenever we tried to speak to him about his behaviour. He did really strange things that made no sense. Sometimes (.3s..) I would hear him sorta talking to himself.* (Victoria)

For these parents, the young adults were physically present but little-by-little mentally slipping away. Gone, snatched away. According to Gadamer (1996) the healthy body is usually taken for granted. We do not often think about how complex the brain is and what it means when it is not functioning properly. In the case of parent caregivers they experience the mental illness of their young adult child as alien. The child becomes a stranger. Health and life as it was formerly understood is out of balance. Other parents described "it" as if an invisible switch had been flipped. Carole had been away for the weekend and upon her return became quickly aware that her young daughter felt unsafe. Her daughter was darting about and looking out the window, and expressing concern that someone was out to get them. At first Carole tried to get her daughter to rest and relax, but soon realized that something much more serious than fatigue was ailing her young daughter.

> *I think I was in shock. At first I thought maybe she was stoned. Like I thought maybe (..3s..) I dunno, like paranoid from too much pot or something. It was like someone flipped a switch in her brain and made her feel afraid of everything. She was hysterical and I was beside myself. I didn't know what to say or do. It was frightening. She was freaky and scaring me.* (Carole)

For these parents their young adults seemingly transitioned in the flick of a switch, suddenly changed, into someone very different. Snatched by an unknown thief - quick of hand. Thomas wondered what happened to his son at school. He described his son as having everything going for him.

> *All I know is that when he went away to school he had everything going for him. He was, um… happy and in good physical shape. He was smart and motivated and won a scholarship. He was outgoing and had a ton of friends. He could do anything he put his mind to. Then this, you know, then suddenly he changed. (tears glistening in eyes) (…5s…) I just wish I knew what happened to him there. When he came home he had completely changed.* (Thomas)

I wrote the following poem to illustrate the feelings expressed by parents. They felt particularly vulnerable to this thief, but also felt the need to put up a fight to rescue their loved one. They were simultaneously angry, full of sorrow and frustrated at a situation that was unpredictable, unwelcome and seemingly spinning out of their control.

Kidnapping Thief

I recoil from you.

I abhor your insistence,

Your sickening gruesome grin, taunting me,

Lording it over me.

He used to be all smiles, an

I can do anything kind of guy

Nothing fazed him

He pushed harder through challenges.

My bright and ever shinning star

The source of my own beaming

Affectionate, thoughtful, and ever helpful

Full of wonder and possibilities, I am enraged

I will not engage

I turn my back on you

Damn you Thief,

He is not for you

(JHW)

Confronting a stranger

Parents made efforts to wrestle their young adult children from the thief. They were generally sad and expressed considerable loss. Parents admitted that they missed their loved ones who had either slowly or instantly become strangers.

> *He's always been, I thought, was so self-assured he could do anything that he set his mind to. And then he couldn't do it. And ah, I knew there was something different about him but I thought, oh, you know, he's just having a hard time*. (Hannah)
>
> *This was not her, she could not focus, she stared in a weird way. She was like a zombie and just needed to be taken care of. My daughter was in their somewhere, but the girl I knew was just gone.* (Sharon)

Hannah noted that she was suddenly aware that something was wrong. She recalls this vividly and uses a comparison between the formerly confident young man and the less capable young man after he became ill. Sharon also notes that when her ill daughter returned home from school, that she did not look or act like the same person. Sharon felt her daughter looked like a zombie.

There was predominately a mood of sadness when parents described confronting the stranger. This stranger was someone who resembled their loved young adult, but did not act like their son or daughter. Bonnie's comments below so clearly illustrate the difficulty of facing the unfamiliar stranger. She laments not knowing her son, no longer being able to recognize or predict his behaviour.

> *His behaviour just got very bizarre. Um, he was spending all his time in the basement, um, by himself, playing music, ah, or watching videos. Um, he became obsessed with a guy where he would say very off the wall stuff, living in his own little world, but he's always been a little bit different anyways. Um, so it was odd, although I remember a few times I said to him, I feel like I don't even know you anymore. So anyways, um, at that time, ah, he was having some rage issues, ah so, that he would get extremely angry, ah, which is so out of character for him, cause he's not normally like that.* (Bonnie)

All the parents were sad and grieved by their young adults' inabilities to connect in a meaningful way with them or with others. During this onset phase of psychotic illness parents recognized that they did not share mutual understandings with their young adult children. Parents noticed the changes in their son or daughter and attributed these changes to something "*strang*e", "*weird*" or "*bizarre*." Several parents recognized that their son or daughter was "*in their own world*" and not accessible or interpersonally present in the usual sense of family communication. Parents often commented upon the unpredictability of their situation and the distressing transformations to "stranger" they witnessed. The time before psychiatric assessment was obtained and a diagnosis confirmed was consistently a time of intense ambiguity (Chesla, 1995). This ambiguity was heightened for parents when the onset of illness was more insidious or potentially confused with the effects of substance use/misuse. Parent caregivers at this early stage of their son's or daughter's illness were drawn into caring practices in response to the perceived transformation of their beloved child into a stranger.

Words that change your life forever

"You have cancer",

"You failed",

"It's inoperable",

"There is nothing more we can do",

"Sorry there has been a fatal accident",

"He is a danger",

"It is psychosis".

"What did you say? I don't understand"

Did I hear you right?"

Did I hear you right?"

Psycho-what?

Psycho-who?

(JHW)

There are a few phrases that we never want to hear uttered in relation to one we love. “It is psychosis,” certainly tops this list. These three words change lives. Health or mental health specifically, is never to be *taken-for-granted* again. It will never be in the *background* again. Concern for wellness will be a worrisome and ongoing companion. Psychotic illness is certainly treatable but it does not generally disappear. There is no cure. Although one can now expect a very impressive recovery, having a psychotic illness requires ongoing attention to health and lifestyle, attention to minimize stressors and oftentimes careful ongoing monitoring of medications. This is not what one expects for their young adult child. “It is psychosis” is a phrase that changes things. Even if the young adult has an excellent recovery, there will always be worries about future episodes and serious relapse. “It is psychosis.” These three little words change family life forever and evoke descriptions from the parent caregivers such as: *“terrorized, living a nightmare, walking through hell, devastating, a battle, creepy, a horror, unbelievable, heavy”.*

Through language, humans set out for one another particular human concerns and discriminations (Taylor, 1985). In the expressive dimension, language establishes understanding between humans, but language is also constitutive. It sets up what we think, what we feel and even what actions we might take. Taylor (1985) suggests that aspects of human experience are constituted by language including our conscious or explicit awareness of things, our feelings and our self-descriptions. In this case, the three words, “It is psychosis" being clearly articulated in relation to the changes parents had observed and experienced in their son or daughter, moves parent caregivers to understand their young adult child's behaviour in a new way. "It is psychosis" raises parental concerns and sets up what is stressful about the situation as well as the way a parent might begin to respond and cope (Wrubel, 1985, Chesla 1995).

"It is psychosis" are the three little words that according to Janet completely changed the way she sees her son.

> *And um, so what I feel now, in terms of um, my son is a profound sense of loss. Um, somehow I feel like, you know, um, I've lost this naive perception and relationship with my son. You know? Where I have to kind of question all the time - is it that he's excited only or is it that he's gonna open up to mania? You know. So you become worried, there is something that just gets tainted.* (Janet)

Janet was not the only parent to describe this transition through the language of diagnosis to a new perspective. Where prior to the "It-is-psychosis" moment she would have used words like enthusiastic, and energetic, she now uses words like mania to describe her son. She acknowledges that her view is no longer naive, and is forever tainted by the perception of mental illness. She is always worried and on alert for signs of impending relapse. From this moment on she looks at her son through the lens of those three little words. "It is psychosis". Life for her has changed forever. The difficulty lies in her understanding of psychosis as an expression of an illness such as schizophrenia. This is a DSM-IV diagnostic assignment that essentially serves to label her son as embodying serious mental illness. For Janet the “difficulty is that the cultural dominance of the medical model in the understanding of human behaviour effectively shuts out alternative understandings of personal experience” (Duffy, Gillig, Tureen & Ybarra, 2002, p. 369).

Similarly Hannah, shares a change in her own outlook and her tendency to try to comprehend the difference between illness and “normal”. Hannah struggles to determine where the diagnosis stops and where her son regains a sense of control in his own life. She struggles with feeling trapped in the complex problem-focused world of mental illness. The diagnosis of bipolar affective disorder has determined her outlook.

> *We would have never guessed mental illness. If you’ve never dealt with it, never read about it or even if you have, obviously you didn’t pay attention to it. Um, so I think yeah, that whole thing took us by surprise. We kept thinking drugs, drugs, drugs. I don’t know. Like we knew something was really wrong, right? After his hospitalization it was hard to know what was normal. It is sad to feel so worried when he is acting silly. You know… [5 s]… is it illness or is he just acting silly and having fun? Your outlook changes so much*. (Hannah)

Also troublesome are difficulties discerning illness symptoms from personality. At this early stage of caregiving, parents are trying to determine the boundaries of illness. Again, the uncertain and ambiguous nature of psychotic symptoms caused considerable confusion. Where do illness symptoms start and end? Generally parents of a young adult with a diagnosis of bipolar mood disorder had a clearer picture of perceived illness symptoms. However, for parents who described a young adult child with a schizophrenia spectrum disorder, there were less clear delineations.

The label of psychotic illness, with its reference to a medical model diagnosis transforms the individual and forever taints the perceptions of those who care about him or her. The labelling event or diagnosis of first episode psychosis creates a new vigilance within caregivers. They are then determined to identify subsequent episodes earlier, at a less dramatic stage. For the parent caregivers, mental health is never again taken for granted. Even when the young adult has a relatively smooth recovery, sitting vigil, always and forever on the alert for worrisome mental or behaviour change becomes the new parenting norm.

Reversed Metamorphosis

While touring the beautiful Butterfly Museum in Niagara Falls recently, I was particularly drawn to the posters and animated videos that depicted the process of metamorphosis from egg to larva (caterpillar) to pupa (chrysalis) and butterfly. When I returned home, I began to reflect upon the notion of metamorphosis and felt that it was a relevant term to describe what parents had witnessed in their ill sons or daughters. Metamorphosis is defined in the Oxford dictionary as “a change of the form or nature of a thing or person into a completely different one”. The young adults experiencing first episode psychosis are obviously not different people but their parents described their behaviour and demeanour as having changed or transformed to such a degree that they were not their usual self. “It just wasn’t like him/her” was a consistent lament when parents’ struggled to describe and make sense of the changes they observed in their young adult over time.

The difficulty of trying to understand the perplexing changes witnessed in the young adult children was magnified by the timing of these emergent psychotic symptoms. Parents were not always able to sort out the differences between the usual behaviours of adolescence and those of early illness. Harold described the following.

> *It was so hard… really almost, aw…aw…impossible to sort out what was going on. I wondered if he was just acting like a spoilt brat, like a teenager always bending the rules. But there were other times that I…I…um.. thought he was acting strange and not really able to pay attention to me. I could not see any um …symptoms of illness. I didn’t catch it and with my background I should have.* (Harold)

Harold is reviewing events that transpired before his son became unable to function at school. He articulates the difficulty of sorting out the difference between an acting-out adolescent and coming to understand events in light of an illness. Harold had professional training, which he believes should have helped him discern the symptoms of psychosis more clearly. Bonnie also had trouble sorting out the cluster of behaviours and events that when recalled with the benefit of hindsight heralded emergent psychosis.

> *I should have figured it our sooner. He was such a sweet guy. He had always been so caring and affectionate. I used to call him "my perfect man". He never caused trouble. Aw… He came through his teens so easily. Not at all like his younger sister. She was such a handful, a troublemaker. (giggles, briefly) He was an easy guy to get along with. Then he started acting different. You know, like he sort of became….an irritable teenager but he was in his twenties. I wasn't prepared for his weird behaviours. It seemed like he was going backwards… Sometimes I didn't know how to react.* (Bonnie)

It dawned on me that parents were describing living through a metamorphosis in reverse. They turned from parenting an adult child who in most cases had left home to pursue educational programs, to finding themselves witnessing reversals. For Harold and Bonnie, their young adult children had been newly emancipated from their parents, living independently and enjoying success in educational settings. They were to their parents beautiful butterflies in flight. Their parents beamed with pride as they shared anecdotes of their young adult's adjustments and accomplishments away from home. Until illness symptoms emerged these young adults were living out their successful launch to adulthood. However, through the onset of mental illness, their soaring to new independent heights was cut short. The young adults and their parents experienced or witnessed painful reversals. These young adult butterflies, experienced significant mental health challenges, which returned them to an earlier, less independent status. These former butterflies were caterpillars again, inching along and sometimes curled up and immobile. This regression was unexpected and completely shattered parents dreams.

Hearing about these reversals and bearing witness to the pain and loss experienced by parent caregivers was the most heart breaking aspect of the parent's conversations. Facing the reversals often evoked tearful but pride-filled reminisces of a former butterfly in flight. Butterflies are free, unencumbered, unfettered, universally cherished and enjoyed. Parents embraced their butterfly and mourned its' descent and even if only temporarily, its grounding. For Sharon, witnessing the reversals in her daughter coincided with having to have her daughter admitted to an inpatient psychiatric treatment setting. She had very painful memories of walking out the locked door and leaving her daughter behind. She came to the difficult understanding that family home could no longer provide enough safety and support.

> *I walked out of <u>that psych unit</u> and heard the door click shut behind us. I immediately started to cry. I was so tired but I didn't want to leave her there. She looked so tiny, so vulnerable, like…well like a child, especially standing beside those big attendants. (giggles nervously; tears form) I <u>felt</u> like running back and taking her home. I didn't know anything about psychiatry and hospitals and forms. I just knew in my heart that she needed to be in a safe place.* (Sharon)

Sharon's description of some of her first moments interacting with the mental health care system depict the fear involved in leaving a loved one in the care of strangers, like the "big attendants". She provided the exemplar in articulating the terror and ambivalence of giving over a loved one to an unknown system of care. Acknowledging reverse metamorphosis was met with a peculiar mix of emotions. Sharon had an embodied response to her experiences with her daughter. She "knew in her heart" that her daughter required care in a safe place although until the point of admission that safe place was construed as the family home. Most often parents wished they could be the ones to help and, indeed, they all tried. Overall there was considerable variation in the timing of help, the nature of the help sought and the location of help. All parent caregivers recalled these significant events with considerable clarity and feeling as if "each moment of time calls all others to witness" (Merleau-Ponty, 1962/2002, p.79). Parents "knew" in an embodied way that they needed to seek assistance. When their young adults' regressions came to light, when the butterflies failed to navigate the assumed path to adulthood and became grounded, parents described, "having a gut feeling," "sensing a change," "feeling strange," and "unable to breath." Les Todres suggests that "body functions in situations as background knowing of how the situation is a whole before perceiving its distinctions" (2007, p. 21). To express this in another way, bodily experiencing is the place where the presence of more than orderly patterns come to us first. Olthuis suggests that the body as a whole functions as a "sensorium, a senser, a knower, a perceiver and a digester" (1997), p. 137). How we experience the world around us is through our bodily presence.

Parent caregivers had a “felt sense” that something was wrong, that reversals were emerging. Sometimes, embodied knowing has the power to say more than what can be expressed in language. Heidegger suggests that intentional consciousness shows itself first and foremost at a pre-cognitive relatedness to a world of concerns. Here “an embodied knowing works to attune us emotionally to our environment whereby we can learn and demonstrate competence in knowing how to deal with everyday activities” (Hyde, 2006, p.37)

When dreams fade

The parent caregivers I met had had dreams and fantasies galore about what their young adult child would become. Like any parent, the hopes that parent caregivers expressed to me in our conversations were for their young adults. These hopes always included those for a promising future, and dreams that their young adults would achieve their potential. Heidegger (1927/1962) suggests that we human beings experience each moment as it relates to our past as well as to our sense of future possibilities.

> Only in so far as Dasein is an “I-am-having-been” can Dasein towards itself futurally in such a way that it comes back. As authentically futural, Dasein is authentically as “having been.” Anticipation of one’s ownmost “been.” Only so far as it is future can Dasein be authentically as having been. (373)

Culturally children and grandchildren hold the future legacy for their family, are evidence of the circle of life and embody the hopes for a better world.

Hope and wishing are intertwined with the idea of future possibilities, since wishing for something engenders the hope that a dream will come true. When dreams or hopes have been shattered by illness, the present can take on greater immediacy or importance (Ewing, as cited in Johnston & Schollar-Jaquish, 2007). Parent caregivers hold onto hope for what lies ahead. Their dream is always and forever about health and happiness. In our conversations, parent caregivers shared many of these hope-filled dreams with me. Without prompting, all the parents took considerable time during our conversations to review and reflect upon cherished memories. They eagerly shared amusing stories of childhood innocence, dreams about vocational aspirations, listed achievements, relived moments of chest-puffing pride, and revelled in cherished successes. Through this reflective recollection parents expressed such enjoyment in their young adult children. However these were moments of mixed feelings. There was an unpredictable emotionally laden pendulum that swung intermittently back and forth between past and present. I likened it to a broken metronome that would miss a beat or two and try again and again to regain the former predictable rhythm. The emotions expressed ranged from joy and pride to sadness and sorrow. The psychotic illness had placed the original accomplishments and future hopes and dreams in a foggy half-light. Parents feared that the future was not quite so hopeful, but they were not without hope. It seems they were afraid to hope, in case these hopes were dashed by illness. Janet describes being afraid to hope.

> *I have some hopes. At the same time, it is silly, but I'm afraid of having hopes. I worry...is this going to be his life?* (Janet)

Through my conversations with parents, I re-experienced over and over again their sense of faded dreams. The dreams shifted away from the past hopes and expectations. Possibilities for the future were set off to the side. Parents' dreams for their young adult child, although somewhat less vividly visualized in light of a diagnosis of psychotic illness, still exist and existed. Parents do not give up the dreams they hold for their loved adult children easily. They simply, gently, and most often silently, without verbalizing it in speech, lay the dream aside for a while. But the dream, although faded is still very much alive. This dream, like an eternal flame is not extinguished.

Embracing possibilities

Parents' dreams for their young adult child with psychosis seemingly required some adjustment to the *world* of psychiatric treatment. Parents' situations also changed, as they had to accept the reversals they witnessed in their young adults. Parents' response to lost dreams was varied. It appeared to depend upon their understanding of what hopeful possibilities remained. Hannah struggled with knowing how to support her son as he began his journey of recovery, but also in articulating what this meant for her own retirement and future. We see in Hannah's excerpt below that she has experienced a turning away from what was once expected. That which was formerly anticipated and relied upon is swept away and a new set of priorities and concerns suddenly comes into view (Johnston, as cited in Johnston & Schollar-Jaquish, 2007).

> *I really don't know what his illness means for his future, or ours? Like me and (husband's name) had always thought that by this time in our life we'd have more freedom. You know, um, um,.. like we always looked forward to an empty nest. (Laughs) We already bought our* <u>*retirement home*</u>*. This whole thing happened at a time when we thought he was on his way. Now everything has changed. He's back at home. I am happy he is back with us, but it is hard to know how to help.* (Hannah)

Turning away from dreams means having to embrace an uncertain future and requires reflection on how best to enhance possibilities for all family members. The notion of the "perfect family" is confronted with imperfection. The advent of emergent psychosis is experienced as an aversive situation, a wrenching away from the everyday, where very little can be taken-for-granted. According to Heidegger, being wrenched away from the taken-for-granted, may through this adversity invite hidden possibilities. Some parents worked very hard to maximize what they believed would enhance normal productivity and protect future possibilities for their young adult children. Sharon consistently worked along side her daughter to support any efforts that would allow her daughter to engage in educational or work roles that were typical for a young twenty-something woman in our culture. Sharon's coping efforts consistently focused on helping her daughter achieve "as close to normal as possible".

> *I just try to help her keep all her options open. We can help financially, so we are happy to pay for her tuition or help with things she needs. Umm. Um…She* <u>*racked up*</u> *quite a bit of debt when she was manic so we helped*

> *her with that. We will do what we can to help her get on her feet. I just hope she can be happy and independent. That's all we want is for her to be as close to normal as possible.* (Sharon)

It seems that Sharon's daughter's illness and the concern about her daughter's employability was a significant worry. Sharon's *background* meanings, her own history and her experiences with parenting her daughter combined with her understandings about bipolar illness comprise her *world* and consequently impact her ability to see new possibilities (Benner & Wrubel, 1995). For Sharon, productivity is an important value and it appears to shape her approach to caregiving. The notion of productivity is also in keeping with cultural norms. Several other parents held a similar understanding. Attempts to maintain 'normal' or coming as close to normal as possible commonly motivated parents' caregiving practices.

Less commonly, parents' patterns of concern brought about caring practices that were more focused upon preventing stress and "not rocking the boat". This resulted in somewhat lower expectations of the young adult and a focus upon preventing relapse by altering levels of stress. Thomas spoke clearly about this particular approach to caring. Thomas felt strongly that a life with as little stress as possible would protect his son from further reversals to his independence and to prevent the possibility of a relapse into psychosis. In Thomas' mind, his son's future could be best managed by avoiding stress.

> *I have tried to keep things calm between us. I have found it better "not to rock the boat". You know, I am embarrassed to admit it but I used to fight with him. (Twittering giggle...) I used to try to change his mind about the way he was thinking. I was just wasting my time because all that stuff was real to him. There was no use trying to prove him wrong. Now I know better. Aw ...I can't change the way he thinks. The medications help with that. I just change the subject and keep the peace. I don't want to stress him anymore.* (Thomas)

Thomas holds an understanding that helping his son to avoid stressful events will keep him stable. Thomas places considerable value upon this approach and discloses how he has altered his interpersonal approach with his son. Other parents took a similar approach of modulating interpersonal or household stress and described these efforts as "like walking on eggshells" and "needing to read his mood carefully to not cause him more stress". To parents who held these worries about their young adult's stress threshold, caring actions often focused upon efforts to enhance mental stability or prevent distress at all costs.

I found it particularly interesting that the possibilities that parent's held for their son's or daughter's future were closely aligned with the diagnosis their young adult had received and the assumptions they held about prognosis. Although it could be said that all parents in this study were engaged in caregiving practices, which focused upon enhancing future possibilities, the range of possibilities seen to be appropriate or available to the young adult were sometimes restricted by parent's notions of a more limited or guarded prognostic outcome. It was difficult to tease out if the prognostic assumptions held by parents were based on the actual recovery challenges that their young adult had experienced or if parents' cultural and highly stereotypical or stigmatized understandings of mental illnesses like schizophrenia or bipolar affective disorder shaped the perception of more restricted possibilities.

Sneaky suffering

On the whole parent caregivers are very careful not show their sadness in front of their ill young adult. They retreat in solitary moments when no one is watching to express their sadness or sorrow. This poem by Teresa Greenwood (1970), an African American poet and mother who experienced her own share of faded dreams and heartbreak describes this as "crying inside".

Inside I am crying,
But my face is silent
Inside I shout loudly,
But my tongue is still.
This is terrible, I feel down
But I know that You can reach down
And pick me out of this dross
A big mama like me

Sitting here so low

I must wipe my eyes

Before the children see the stain

The tears have left. (Greenwood, 1970)

Greenwood grieves in solitude. She puts on a brave face for her children wiping tear stains from her eyes before the children can see them. Parent caregivers do this too. The notion that at times one may be *inauthentic* is not unusual. Even to Heidegger, who spent much of his work guiding human beings back to the question of the meaning of *Being* and toward *authentic* selfhood, understood that it is necessary to be lost in *inauthenticity*; but then, another choice confronts us (Eddy, 2008).

Heidegger (1927/1969) opines how the *authentic* self is at first, before it is fully authentic, lost in the "*they self*" of others. At some point, if authenticity is to be achieved, the self needs to choose to abandon living for others, and choose to live for one's self. Heidegger goes on to say that everyone who is going to move toward authenticity must experience a "*making up for not choosing*" (p. 248) to be *authentic*. Making up for not choosing signifies choosing to make this choice – deciding for a *potentiality-of-being*, and making this decision from one's own self. In choosing to make this choice, Dasein *makes possible*, first and foremost, its *authentic* potentiality-of-being. But because Dasein is lost in the "*they*," it must first *find* itself. In order to find *itself* at all, it must be "shown" to itself in its

> possible authenticity. In terms of its *possibility*, *Dasein is already a potentiality-for-being- its-self, but it needs to this potentiality attested.* (p. 248)

Almost all of the parents described living *in-authentically*, putting on a 'fake' brave face. They particularly did not want to let their young adult child with psychosis know how sad, or how consumed with grief that they felt. Feelings of grief and sadness had little opportunity for expression and parents' suffering was not overtly acknowledged. They suffer silently in solitude. My textual attempts to explain and interpret the emotional pain parent caregivers experience in response to the emergence of mental illness in their son or daughter were fraught with difficulty, partially perhaps, because the suffering is hiding, masked by a public façade of optimism. Not all suffering involves physical pain. Arendt (1959) describes suffering as the "most private" and "least communicative" (p.46) of human experiences. In the talk that connects people and creates a common *world*, compassion is often marked by muteness around pain and suffering (Arendt, 1977). Parent caregivers' compassion invokes intense empathy, "being so stricken with the suffering of another that one suffers as the other does" (Kavanaugh, as cited in Johnston & Scholler-Jaquish, 2007, p. 21). Compassion then, is about co-suffering. Through compassion, parent caregivers experience suffering and pain along with their young adult children. Hannah, shares this co-suffering experience.

> *I really have no choice as his mother to feel bad for him. My heart breaks for him every day. He has been through so much and he continues to suffer with voices. I love him. I just want him to be well, and have a good life. I*

> *feel so sad when I think of how he used to be. It hurts. Those memories are hard to think about. You know, sometimes, when he is out, I find myself crying for no reason. But um…I don't ever cry in front of him. I don't ever want him to see how sad I am. I don't want to make him feel worse.*
> (Hannah)

Hannah keeps her feelings of loss to herself. She does not want her son to know the depths of her sadness. She suggests that her feelings of loss, if overtly expressed would bring upon "worse" feelings for her son. Hannah wants to protect her son from any "worse" feelings of being responsible for her (concealed) feelings of sadness and grief. Carole describes hiding her feelings of sadness from others but particularly hiding these feelings from her ill daughter.

> *It is difficult to show your real feelings. You just try to be upbeat, you know (…4s…) Like I am sometimes literally crying inside when I see her looking so down and I feel helpless. No one likes to see their kid depressed. I can just tell by the expression on her face. So…I guess I dunno…just try to be more cheerful. I just do what any mom would do I think. My mom always tries to cheer me up whenever I am down. Sometimes I get out the photo album. We flip through it together and remember happier times. I think it helps me as much as it does her. It helps to remember that we had good times together. It isn't good right now, but maybe it will be again. That is what I hope and pray for.* (Carole)

Carole clearly shows how she sees her role as somehow, (seemingly no matter what it takes), making things better for her daughter. She also shares that this is what a mom does in her *world*, the same *world* where coincidently her own mom continues to cheer her up. Carole covers up her own sadness, in an effort to offer her daughter a more hopeful *present* by reviewing their memories of a shared past. Carole notices her daughter's suffering and responds to it in a way which both meets her daughter's assumed needs, but also inadvertently helps her to feel less alienated from her own feelings and also more hopeful. For Carole, the intergenerational mother-daughter relationship is the context or *world* in which she understands that her own needs and feelings are secondary to those of her daughter. Robert Bear (2011) provides a poetic description of this kind of mother-daughter love.

Possessing little, she offered me much.
I was neither protected nor coddled nor spoiled.
She taught me to abhor pity,
to pay my way or to do without.
to make my own decisions.
to live with them.
And from her I learned of the sweet scent of hope, and
the power of forgiveness.

(Bear, 2011, p. 18)

To move beyond the potential for self-pity or a negative focus upon shared suffering (which closes down parent caregivers' ways of *being in the world*), opens up possibilities for finding meaning in that suffering (Toombs, 2004). By creating a shared meaning for suffering, parent caregivers like Hannah and Carole along with their ill young adults come together to create solidarity and diminish the isolation and felt alienation (Harris, as cited in Johnston & Scholler-Jaquish, 2007). Most of the caregivers in this study commonly expressed examples of selflessness. The actual description of selfless behaviours varied from parent to parent but their efforts to conceal their own sadness and focus instead on the feelings or mood states of their ill young adult was almost always evident in each conversation.

When dreams are shattered

Perhaps not surprisingly, the conversations with parent caregivers frequently lead to me reflecting upon and contemplating the power of dreams. Following the conversations and throughout the data synthesis I often reflected upon the influence of dreams. I reflected upon the dreams we hold for both our children and ourselves and how in some ineffable way these dreams act to sustain us. What we hope for shapes our concept of the *future*. Alternately "the fracturing of a person's dreams is a horrible thing" (Bear, 2011, p.192).

I am no stranger to shattered dreams. I recall how lonely I felt in the early stages of the onset of my husband's illness. Although I had the support of my family, I no longer had the *taken-for-granted* support of my best friend and life partner, my husband. I took to acting deliberately cheerful, faking an upbeat demeanour in his presence even though my heart was literally breaking inside. My dreams of security and an unobstructed future were shattered. Did he still have a bright future? Did we have a future? Was this a bump in the road or the end of our road? The experience of my own suffering consumed me, eating up most of my energy and my usual confidence. I turned away from the everyday and the *taken-for-granted*. I had to turn away from the *future* I anticipated (I was expecting our first baby at this time) and cope with a whole new set of circumstances and concerns. New priorities came into view. The fantasy of the perfect, growing family painfully dissipated and I needed to re-examine my situation and consider other possibilities. However, the consideration of other possibilities was a long and circuitous journey. I was moved in a different direction than that which I had originally assumed. My fractured, shattered dreams fuelled my path. It was a journey of necessity which too often felt like a vicious cycle, born out of the difficulties and suffering brought about by my husband's mental illness. However, recalling again what Heidegger would say of this adversity these were moments in which possibilities were certainly hidden. Although the illness onset and the wrenching disjuncture did not offer quick access to the meaning guaranteed to be acceptable to the self (Johnston, as cited in Johnston & Scholler-Jaquish). Parent participants in this study described their quest to find acceptable meaning as a journey into ominous territory.

For the parent caregivers who conversed with me, a variety of shattered dreams accompanied the confirmation of a diagnosis of psychotic disorder in their loved young adult child. For the parents, a first episode of psychosis in a loved one brought with it an unforeseen future and potentially unfulfilled dreams. Being born into a world where our cultural understanding of serious mental illness is often perceived of as a downward spiral of chronicity and a substandard quality of life, the meaning of a first episode of psychosis left parents feeling bereft of the dreams they once held for their child's future.

Throughout this early period of their young adults' diagnosis and initial treatment for serious mental illness, all parents experienced a predominant mood of sadness. Each of the families who participated in this study described having entered the treatment system reluctantly. For most it was frightening and conjured up unpleasant images and stereotypes. For parents who believed they had nearly completed the cycle of child rearing, the concern about a mental illness in their young adult disrupted the natural rhythm of family life events and seemingly shattered future dreams. Notions of successful independence and productivity, so much a part of our cultural norms, were thrown into question. Once the diagnosis was confirmed, Sharon, initially felt a sense of relief. A few weeks later she recalls allowing herself to think about the *future*.

> *I remember she was still in the hospital and I was trying to catch up on my sleep. Aw… there, there was an afternoon when instead of visiting her, I decided to have a nap. She seemed to be getting a bit better and I was relieved. But, you know, as soon as I lay down, I became intensely anxious. It occurred to me that even when she was released from hospital she would still have this illness. I could see she was getting better but I hadn't allowed myself to think about the fact that there was no cure. I felt panicked by this realization. Seriously, I felt I couldn't breath. It was like my hopes for her were all of a sudden in question*. (Sharon).

Frank describes this early stage of coming to awareness as being stunned. His former dreams for his son disappeared in those moments.

> *I was stunned. I immediately thought of his school. He really wanted to finish college and I figured that it was all over for him. I really thought that all people with mental illness get institutionalized. I was so ignorant. I won't lie, I cried when the doctor said he was mentally ill. All my dreams for him disappeared. Then the doctor said "You know Frank, this is treatable" and I swear I could have kissed her*. (Frank)

Reflecting on the original hopes and aspirations provides parents with an opportunity to recall the dream and perhaps adjust it as a more flexible, and fluid template for recovery and reconstitution. They certainly grieve the loss of this original dream but within their suffering, they most often find new possibilities. But still, a remnant of that initial sorrow remains. Always needing to include space for the next appearance of mental illness keeps resetting the colour, brightness and hues of dreams. But some dreams appear to die harder than others. Janet thinks that part of her struggle to relinquish her dreams for her son was remembering so clearly what her hopes for her son had been.

> *In the beginning of all this, I would daydream sometimes about what might have been. For me, I think this reflection on my dreams for [her son] was a way to work things out. For me, it was a way of letting go of some dreams. I am not saying that I don't still have dreams; they are just different, sort of scaled down dreams. For me um, well, I think maybe, hanging onto some of my former dreams was standing in the way of accepting the moment. [Son's] suffering is my suffering and holding on to unachievable dreams increases that suffering. I find it easier to live for today. I live, um I mean, .. I try to live with faith for a better future for us all.* (Janet)

Hall (2004) suggests that suffering both tests and prompts learning who we are and of what we are capable. For Janet, this involved adjusting to the un-dreamed of realities. This did not mean that she had given up on all dreams for her son. She still held hopes for his future, but the focus and scope of those dreams was readjusted. Later in a second conversation, Hannah shares the following comment, which is perhaps an exemplar of the kind of learning to which Hall refers. Hannah speaks to the growth in her family and the pride she feels in their ability to overcome her son's scary illness experience.

> *His illness is in some ways the worst thing that has ever happened to our family, but it has been good in another way. I bet that sounds crazy …right? [smiling, giggles briefly] It is eye opening, and through this whole time, this whole scary experience, we have all become closer. We have all rallied for [son] and I am proud of the way we have been able to get through all this. It sure hasn't been easy for any of us but we have survived and become stronger. …[3s]… I am just so proud of him,…of all of us really [tears up].* (Hannah)

The mere inescapability of the situation necessitates merely dwelling with *what-is*. Dwelling with *what-is,* has been described variously by parent caregivers as, "a maze", "a puzzle" and as a "scary" and "formidable struggle". Frank (1995) describes this as a wilderness experience. Marcel (1963) describes this experience as exile, being alienated, cut off and banished from access to support and authentic engagement.

Singing the Blues

When you lose a loved one you grieve, you mourn, you feel a solitary emptiness and from then on you conjure up memories to fill the void. (James, 1998). It is a forever loss with no hope of resurrection. It is an ending and one speaks of the deceased love one in the past tense. Grief theorists have written about stages of this loss and many popular books have been published to aid those who grieve (Kubbler Ross, 2007). As a matter of fact there is a whole industry that surrounds the loss of a loved one including for example, funeral homes, cemeteries, memorial stones, and grief counselling. Our culture provides us with clear, concrete ways to reach out to those who grieve the loss of a dear family member. We all become practiced in words and actions to respond to another's grief. Usually people say, "I'm sorry for your loss." People gather around at funeral visitations for support, make casseroles, and reach out by telephone. The loss is acknowledged overtly and attempts are made at least on some level to console the bereaved and reduce their suffering.

However, the grief experienced by parent caregivers of young adults with first episode psychosis is much less clearly defined. There is a grieving process of sorts but it is distinctly different than that which focuses upon the finality of the death of a loved one. The parent caregivers grieve lost dreams and lost health. They grieve the mental illness of their young adult. But this grief has few places to express itself. Their sadness and isolation mounts. This old 1960s blues song by Sam Cooke (1962) depicts this desire to share, to unload the sorrow they feel.

Sad Mood

I wish somebody would come and ease my troublin' mind
I wish somebody would come and ease my troublin' mind
oh yes I do
why won't somebody come and ease my troublin' mind
I sure wish somebody would come and ease my troublin' mind
I wish my baby would come and tell me everything's alright
I sure wish my baby would come and tell me everything is still alright

oh yes I do
they tell me when you tell somebody your troubles
trouble fly away from you
I'm looking, looking, looking for somebody
I can tell my troubles to
I sure wish somebody would come and ease my troublin' mind (S Cook, 1962)

This desire to find someone to share one's troubles with is perhaps why parent caregivers in this study consistently and spontaneously mentioned how valuable it was to have access to a member of their ill child's treatment team with whom to talk. The ability to share these difficult feeling states with team nurses was especially valued. Bonnie provides an exemplar of the impact of having someone with whom to share her thoughts and worries.

> *I have really relied on [nurse] to help me through this. Sometimes I don't know what I would have done without her. She always made time for me and provided me with a place to unload. It was nice to know that I was not to blame and that there were things I could do to help. She taught me so much. Aw, but um but sometimes the sessions were just about me. Sometimes this meant just sitting with me, letting me cry, sharing the sadness I felt at first*. (Bonnie)

Bonnie describes her sessions with the clinic nurse as a safe place to unload her sadness. She speaks to the need to work though her own sadness in a non-blaming relationship. Bonnie needed to offload the guilt she was experiencing too. This relationship with the nurse was an essential safe place.

Leaving Normal

Throughout the synthesis of this study I struggled to articulate what I experienced in the midst of the time I spent immersed in conversations and then subsequently within the transcripts. Much has been written about parents grieving mental illness and I would agree there is a profound sense of loss when a loved one develops psychotic illness. The onset of serious mental illness is indeed a very sad and shocking time. Harold tells us that everything has changed and he grieves that fact that a return to "normal" is unlikely:

> *That everything, I mean, things about, um, um, everything you expected or thought about doing, has changed. Yeah, we know that, I mean, what's the prognosis even if things go well? Anyways, things are not going to be absolutely normal. <u>Let's face it</u>.* (Harold)

Janet faces her grief in characterizations of others as "happy" families. The onset of mental illness has transformed her view of her own family from normal to abnormal. She covers her grief with a twittering laugh, and makes light of the re-conceptualization of her family as abnormal.

> *I see other families whether it's a movie or just any family or, or here some of my, you know, acquaintances say, oh my son this, my child that. And I thought, you know, gee, you know you are a normal family. (twittering, laugh) And, um, that's the sadness, and that sense of loss, like*

> *I, I know the things that have changed, you know. I don't want to classify things as normal, abnormal, but that is what it is like. We are not normal anymore.* (Janet)

We all hold a perception of the normal family, but this perception rarely includes a mentally ill family member. The loss of one's sense of being normal is grieved indefinitely and most oftentimes in silence. It bubbles up when parents are forced to confront their perceived differences from other "normal families". It catches them up when their young adult has a little relapse or resurgence of symptoms. It is even more overwhelming when they have to confront the prospects of additional losses.

Considering suicide

A potential for suicide is something that generally evokes a gut wrenching terror in caregivers. As fellow humans, we are culturally and socially called to be concerned and ever watchful for the signs that might suggest a deadly loss of interest in life. The label of mental illness in our culture seems to further amplify concerns about suicide. The diagnosis of first episode psychosis, especially in the form of a mood disorder changes the perspective of safety. This meaning was shared by most of the parent caregivers. In facing the risk of suicide, parents tended to err on the side of caution. The potential suicide of their young adult children was a powerful concern and evoked feelings of anticipated loss. To these parents, the diagnosis meant increased risk. It raised the understanding or anxiety of what Heidegger called *moving toward death*. The possibility of losing their young adult children to suicide was a pervasive fear and substantially shaped caregiving behaviours.

> *The thing that I do worry about, and it's always in the back of my mind, now it, it, it's been a while so it's not as prevalent as it was, but every time my husband and I would go away, cause we go away a lot, so we would go …We would go away for four or five days and my son would be on his own and I'm always, always worried that he might do something like take his life or whatever. I mean* <u>*not*</u> *that he's ever said I'm gonna commit suicide or I want to end my life, but it is* <u>*always*</u> *in the back of your mind, is my child going to be safe when I'm gone? I worry about him all the time. I have a, a, dah, another child who's younger, I don't worry about {that child} at all, but I worry about him.* (Hannah)

Hannah admits being constantly accompanied by this nagging worry. The worry was never far from her thoughts. The fear of loss to suicide makes her afraid to go away to her vacation home and leave her son alone. Her other child, although younger, is not a source of worry. Her worry is for her mentally ill son. Similarly, Janet is overwhelmed with worry that she might lose her son. She described it as the thing that keeps her awake at night and consumes her waking hours.

> *And, and I, worry about the future. I worry about him all the time. I just can't help thinking about him doing something silly, something impulsive. Even when I am lying in my bed at night, I am listening, making sure he is*

> *still in bed. I can't imagine what I would do if he did something to himself.* (Janet)

Frank is more succinct in describing his worry:

> *After that (the diagnosis) I would say, well obviously you watch him a lot closer too, right, cause you think: oh is this kid all of sudden going to go off the edge or kill himself?* (Frank)

The label of emergent psychotic illness brings with it a number of misperceptions and evokes very real fear and active worry about the possibility of loss through suicide. It is the predominate worry that keeps parents awake at night. Mental illness in a loved young adult son or daughter most certainly ignites significant fear of potential loss.

Grief and Sorrow

Grief is defined as deep mental anguish arising from the loss of someone or something held dear. Parents certainly experience significant loss at this early stage of caregiving and through my unfolding conversations with the caregivers, I began to bear witness to this experience of grief. This was one of the surprises in my data synthesis. I expected grief to be a substantial exemplar but it was there in a much more defined way than I had foreseen it might be. Parent caregivers expressed sadness about their young adults' loss of health, and faded dreams. They understood their loved ones were ill, and instead spent their own energies engaged in activities to prevent possibilities of further illness or relapse. I suspect that their young adult's stage of illness onset coupled with intense support in the form of a specialty early intervention team ameliorated some of their grief.

From the earliest acknowledgement of a diagnosis of psychotic disorder, parent caregivers live with ongoing sorrow. Chronic sorrow was first described by sociologist Olshansky (as cited in S. Roos, 2004), who described this as a profound sadness experienced by parents who have a child with a disability. The feelings are normal responses to a situation (like emergent psychotic disorder) where there is no predictable end to the loss experience. Common feelings of sorrow expressed by the parents throughout my conversations with them included: "deep pain", "emptiness", "fear", "guilt"," anger", "resentment", "feelings of unfairness" and as stated earlier, "being cheated" or "robbed". The following quotes from parent participants clarify this notion of sorrow.

> *At first we were relieved when she was hospitalized and we finally had a name for what was wrong. We were hopeful she would get some help and just be her old self again. But it is such a long process. (Sharon)*
>
> *The second episode of mania was worse than the first. I had hoped he would just take the meds and not go back.* (Harold)
>
> *My sadness came on slowly when the reality of this thing sunk in, I just bawled like a baby when they told us he was psychotic.* (Frank)
>
> *We cried so much, we still cry sometimes. We hope for the best but prepare for the worst.* (Hannah)

> *It is hard to think ‘bout her leaving home. I hope and pray this can happen for her.* (Carole)
>
> *It felt like we had lost him. He was so changed until he connected with the program. Now we hope he doesn’t quit.* (Victoria)

The ill young adults continue to be a predominate focus of parent caregivers. The uncertainty of how things will turn out leads to parents consistently modulating hopes to prevent disappointment and potential despair. They “hope for the best”; many rely upon their faith and pray for positive outcomes. They experience sorrow; they respond to this lived loss by holding onto hope, and modulate this hope with a healthy dose of reality. Reflections on parenting and the limits of this caring role conjure up a reminiscence of the poem On Children from *The Prophet*.

You may give them your love but not your thoughts.

For they have their own thoughts

You may house their bodies but not their souls,

For their souls dwell in the house of tomorrow, which you cannot visit.

Not even in your dreams. (Gibran, 1923)

Parent caregivers continue to live, and continue to hope despite their grief and sorrow. The word sorrow is defined as ‘distress of mind caused by loss, suffering or disappointment’ (Oxford Online Dictionary). It is from the Latin word ‘*anxifer*’, which is also interestingly, the root of the word anxiety. Parents live with an ongoing sorrow, an all-consuming kind of anxiety which distresses their minds and searches for hope. Angelou is a particularly eloquent African American author who often exposes distress in human experience. I first encountered her work when I read, “ *I Know Why the Caged Bird Sings”* several years ago. She has an ability to say profound things in such succinct and thought provoking ways. The following passage from Angelou comes from her 1993 book “*Wouldn’t Take Nothing for my Journey Now”.*

> Life is pure adventure, and the sooner we realize that, the quicker we will be able to treat life as art: to bring all our energies to each encounter, to remain flexible enough to notice and admit when what we expected to happen did not happen. We need to remember that we are created creative and can invent new scenarios as frequently as they are needed. (Maya Angelou,1993, copyright permission obtained from Randam House Publishers).

I think this passage speaks to the experience of parent caregivers and the way they continue to push through their feelings of loss and sorrow to find brilliantly creative ways to invent better outcomes for their young adult children with psychosis. Holding hope for a brighter future certainly invites creativity.

Wishing for a brighter future offers parents the possibility of being and becoming different from the being in which they currently find themselves.

Stepping carefully over slippery stones

Successfully navigating the slippery stones in one's *world* requires deliberate focus upon sure footedness and with an eye to the future on the horizon. Not attending to the current moment has the potential to alter the journey or even end it prematurely. Frank describes this careful process of stepping carefully.

> *I carefully pick my battles with him (his son). I let some things slide. I cut him some slack in some areas. He takes a little longer to do things, so what? Hmm… He went back to school and passed. That is what counts. He has quit smoking up. That is what counts. He takes his medications. That is what counts. If his room is a mess or he forgets to fill up the car with gas. I just bite my tongue. That stuff really doesn't matter. I see him trying to get back on track. I just want to be there for him.* (Frank)

The story of stepping carefully on slippery stones is what I understood from the parent caregivers. The stories they shared with me revealed their capacity to traverse slippery stones, to weather enormous difficulties and to cope with whatever was in front of them. Throughout the difficulties they encountered with their ill young adults they seemingly always found ways to creatively rise to the challenges and even though they might misstep and fall into unwelcoming waters and perhaps even ending up with a 'soaker' or worse, they still make it through. They do what they need to do today, in the *present*, in the hope of preserving a better *future* for their loved adult child. They believe there is hope, they hold onto hope and even if they are sinking in mucky water they still persevere. They risk stepping on slippery stones to preserve a better *future* for their young adult child. Interwoven throughout the parents' stories is a sense of angst and groundlessness. Heidegger suggests that the possibility of meaning arriving as potential that is hidden in the very experience of meaninglessness (Johnston, as cited in Johnston & Schollar-Jaquish, 2007). In angst there lies a possibility of distinctive disclosure.

> This individualizing fetches Dasein back from falling prey and reveals to it authenticity and inauthenticity and possibilities of its being. The fundamental possibilities of Dasein, which are always on my own, show themselves in Angst as they really are, undistorted by innerworldly beings to which Dasein, initially and for the most part clings. (Heidegger, 1953/1996, p. 178)

Heidegger helps us to understand that the '*they-self*', through adversity has an opportunity to become an individualized *authentic* self.

In this chapter unfolds the theme of transformed dreams. It encompasses parent caregivers facing the loss of health in their young adult children and the ongoing sorrow they experience as they attempt to negotiate a new kind of normal within their family. Next in Chapter Eight, I describe the closing story of enduring love.

CHAPTER EIGHT

“A parent’s love will endure the perils of today and the heartaches of tomorrow.**”**
Anonymous

Enduring Love

Next I articulate what I came to understand about parental love and the various expressions of that love. Parent caregivers’ love and concern for their young adult child’s wellbeing helps them cope with the stress and uncertainty of first episode psychosis. The ill son or daughter was always the focus of a substantial portion of parents’ energies and their actions were continually motivated out of that love and concern. Facing the fearsome dragon of psychosis quickly transitions parents into caregivers and evokes within them multiple anxieties; motivating behaviours that are lovingly intended to minimize diminishing possibilities. Laying down one’s life for a loved child, wanting to trade places and tolerating ongoing uncertainty and likely exhaustion embodies the parent caregivers’ harried journey through first episode psychosis. The enduring love of which I speak is defined as a love which bears adversity, involves continued patience, perserverence, and a strength of commitment (Oxford Online Dictionary). It is a love which bears up during times of adversity and suffering. It withstands the tough times and continues to seek possibilities.

Welcome home stranger

How many times have we heard or said those words. “Welcome home stranger”. This greeting is often meant as a form of welcome for someone who has been gone for just long enough to be out sight but never really out of mind. I have used this expression myself when a family member or close friend has returned from their holiday travels and has been missed. It never means that I am literally welcoming a stranger. I am welcoming home a familiar friend or family member. I fully anticipate that they will tell me of their travel adventures, perhaps show me their photographs and will also delight in being ‘back home’. They are familiar; I have missed them and they belong to me in some ineffable way.

Welcoming Home a Stranger

Fighting the dragon is the metaphor that I have used intermittently throughout this dissertation to describe the many ways that those with emergent illness and their parent caregivers are shaped and transformed by the experience of a first episode of psychosis. For most of the parents, their stories of initial awareness that the beast of psychosis lurked within their loved adult child came to them most clearly when the adult child was at a distance. Most of the young adults were away at school, other young adults had suddenly and without warning fled from the parents’ home to other distant cities. Another young adult was incarcerated and yet another, although at home, was separated from parents who were coincidently away on a mini vacation at the time. The moments when parents fully comprehended that their young adults were seriously mentally ill, led to a building crescendo of crisis that ultimately culminated in the process of psychiatric assessment and treatment. For most of the young adults, that meant being delivered home as unfamiliar strangers. For parents these heart breaking and gut wrenching moments of waging battle with the dragon were the most difficult. They saw their loved young adult children as having been transformed by a beastly dragon into a stranger. It meant that the usual and expected *taken-for-granted* communication and affection within their relationships were concealed from view. All parents in the study confirmed the perception of their loved ones as strangers for whom they felt a deep sense of responsibility. The face of the 'stranger' constitutes in itself a demand that he or she be taken care of and commands parents to serve this 'Other' (Levinas, 1990). This care is given without expectations of reciprocity, even if it should cost our life. According to Levinas we are not free in relation to the other.

Although some parents had held concerns about their young adults for some time, the earliest moments of witnessing a stranger were at minimum anxiety producing and terrifying at worst. The word stranger is from the old French word 'estranger' and means 'as one belonging to another family, or another nation' (Oxford Online Dictionary). It also depicts the notion of 'a foreigner or alien'. So in effect, the dragon of psychosis is perceived of as having transformed a loved one into an alien, no longer quite recognizable as part of the family. To the parents, the loved adult child is "in there somewhere". What must that be like to perceive that one's young adult child is somehow trapped, concealed or lost within the body of a stranger? Carole describes her daughter as "stuck in another reality"

> *When I saw her becoming so agitated, I didn't know what to do. She wasn't making any sense. I tried to reason with her and reassure her that she was safe, er ..um, that we were safe and that no one was coming to get*

> *us. I tried to calm her down but she was* <u>*stuck in another reality*</u>*. There was just no talking to her. She didn't make sense*. (Carole)

Carole and her daughter did not share the same understandings in their *world*. When psychosis touches the mind of an individual, that person may act and behave in ways that are at times completely at odds with social norms or the basic rules of family life. The sufferer acts like a stranger, doing things that are out of character or frankly perplexing. Parents are challenged to make sense of situations that on the surface at least simply do not make sense.

Victoria describes "stranger" behaviours in her son and how difficult it is to have him act strangely in front of the employees who work within the family owned business.

> *So, we've had him here, but it's just, it's hard having him here and having our workers see him, because socially he has a lot of things that he does that…annoy me. And are annoying to other people, and I just don't know, I don't know how to get him, to break him of some of his bad habits, but ah, you know… [her eyes were searching for acceptance and agreement]… things that you know that are not socially acceptable. We do discuss 'em with him. Like he is a person that picks his nose a lot and he would just, you know, be here and he would put it on the wall or he's a person that spits a lot. And just, you know, like the things that come with it.* <u>*Yes*</u>*? But here's the thing, the funny thing is, these are the strange things*

that helped me realize that he was sick. When I moved, there wasn't one room in our house that didn't have spit um, in it. (Victoria)

Not only does Victoria describe the actions of a stranger who is behaving outside all the family and social norms but she needs for me to understand that this is not the way she raised him. Her son is currently a "stranger" so unlike the well mannered and studious young man of whom she spoke earlier in our conversation and with such pride when he was in grade school. This is a common concern. All the parents spoke of the actions of a stranger that was not reflective of family norms and values. Through welcoming home her "stranger" she had to tolerate, offensive "boogers" and "spit gobs" and come to an uneasy understanding that this was a function of illness and not of poor manners. It put me in mind of a verse by Margaret Johnson Griffith.

To My Son

Do you know that your soul is of my soul, such part
That you seem to be the fiber and cord of my heart.
None other can pain me as you dear, can do
None other can please me or praise me as you.

Within this simple verse is the heart of the concern about the stranger being welcomed home. Our children and the way they act and behave can bring parents' praise or pain. Our children are the mirrors by which we see a reflection of ourselves. As parents, our sense of esteem and identity is entwined by “fiber and cord from our hearts” and a bonding of souls for whom no outsider can grasp the significance. So even when the loved adult child is ‘trapped inside’ a perceived stranger, parents continue to love, to accept and indeed forgive. They resolve to create an infrastructure of love and support. Parents continue to hold hope for better and more familiar moments. Most parents were tireless in their efforts to reacquaint the “stranger” with family life and norms. They were lovingly accepting of social transgressions and transitions. Frankl (1946/1984) suggests that the essence of being human is this kind of natural love. Harold describes his loving concern for his son.

> *I was wondering how to reach him. He was up all-night and slept all day. I was desperate to make contact with him, to just try to see if there was anything I could do. He. Um.. we … were in the same house but never saw each other. I think, well maybe it was his way of coping but I felt afraid that he was getting worse. Aw, I just had to work it out that I was up in the night too. I would stay up late to just see him and reassure myself. I needed him to know that I cared about him. I am his father. I just wanted him to know um , well um I was there for him. No matter what!* (Harold)

Although it is often difficult to maintain the usual dialogical relationship with an ill young adult child, parents like Harold tried their best to keep the relationship open. For most parent caregivers this was seen as a natural outcome of being a parent. When we love another, perhaps like Hannah loves her son, we take a “beautiful risk…a risk worth taking. For when, in spite of the risk, a gift is given and received, both giver and receiver experience a miracle of unmerited grace, the kind that makes all the difference in life" (Olthius, 1997, p. 149). According to Levinas (1990) such close relationships make us 'hostages'. We cannot take for granted our own freedom to act. Hannah shares her view on this deep close love.

> *He was being just horrible to me. I have never heard him use that kind of language. He called me terrible names. Um ...[6s]... I was shocked. That is when I knew that it was illness yelling at me and not my son. He is usually such a quiet, sweet young man. Well I just didn't let him get to me. I just needed to get him some help. I went into protective mode the way any mother would. You just do what you need to do. Any mom would try to help her kid.* (Hannah)

Hannah believes that her caregiving role is inseparable from being a mother. She shares that any mom would do the same. Found within her comments is her commitment to her son born out of her natural love for her son and her poignant ability to forgive. She positions herself to best help him, despite the fact that he has called her terrible names, and has been yelling at her. Her shock, translates into care-seeking behaviours. She responds out of a mother's love. The expressions of parental love for their ill young adult child varied from parent to parent but the selflessness was evident. The parenting stories and the care and concern within the stories shared with me during conversations were moving. I wrote the following to poetically represent the seemingly inestimable depth of a parent's love.

A Parents' Love

A cool cloth applied to a fevered brow

The Band-aid with smelly green ointment pressed on skinned knees

The spit bath to wipe chocolate popsicle dribble from a chin

The command to "stand up straight" and hold one's belly in.

The encouragement to make good decisions

The unfailing support when these decisions turned out to be mistakes

The cheer to dream big and reach one's potential

The sweetest of caresses when life is hurtful or unfair

A reassuring hug to mend a broken heart

Faithful prayers for safety

Forever love, given freely from the soul who knows you better than you know yourself

(JHW)

There is a special loving bond between a parent and their offspring. It is not just a physical presence. It is a sensing and feeling borne out of intense love and concern for another. Buber (1970) suggests that “love itself cannot abide in a direct relation; it endures” (p. 147). *Being-with* is a large part of the parenting role, although the caring and loving, parent-child relationship may not always be reciprocal. Parenting, establishes a relationship that goes “beyond the possible”, a state in which Levinas (1990) suggests a parent can see the other’s (the young adult child’s possibilities as your own (p.83). Parenthood is the deepest form of relationship.

Fix You

Throughout the months of engagement with this inquiry, I came to understand that no matter how old the child, parental love is sustained. Heidegger suggests that the way humans are engaged in the world is set up and bounded by what *matters* to them. What matters to parents of those with emergent psychosis is seen in their engaged actions and caring responses to this worrisome experience. Their motivations are pretty simple. They act to make things “right” for their young adult children. The emergent psychotic illness makes parents feel *unsettled*. According to Heidegger (1927/1962), *anxiety* makes one feel “unsettled” and is revealing. *Anxiety* discloses Dasein, which opens up future possibilities. The threat of psychotic illness in a loved young adult child brings about anxiety that communicates that life is out of balance (Ewing, as cited in Johnston & Scholler-Jaquish, 2007). The song by *Coldplay* called “Fix You” summarizes the wholeness and unselfishness of parent motives in response to their felt anxiety.

When you try your best but you don't succeed

When you get what you want but not what you need

When you feel so tired but you can't sleep

Stuck in reverse

And the tears come streaming down your face

When you lose something you can't replace

When you love someone but it goes to waste

Could it be worse?

Lights will guide you home

And ignite your bones

And I will try to fix you

(Coldplay, 2005)
Words and Music by Guy Berryman, John Buckland, Will Champion and Chris Martin

I first heard this song on the radio and then many months later saw it translated into a touching contemporary dance, choreographed by Travis Wall, on the American 2010 version of the hit show “So You Think You Can Dance.” This dance captured my imagination and tugged at my heart. It touched me and moved me to tears. The dance aired during the time when I was having conversations with parent caregivers and it resonated with me about the lengths one will go to in aid of a loved one. Carole suggests there is nothing she would not do for her daughter.

> *If I could buy her a cure, I would do it. I would sell my soul if it meant she could have a normal life. I just want to, I dunno, make it better, to make her better. It isn't like a skinned knee that just needs a Band-Aid and time to heal. It is so much more complicated. I just wish I could find a way to give her the kind of life she deserves. I..it, um, breaks my heart to see her so alone and having lost her hope for the future. I wish I could do something to take her pain away*. (Carole)

Caregiving parents experience the exhausting and tear filled attempts to fix their son or daughter and restore them to health. Frank speaks to the futility of preventing his son's illness.

> *I could see he was all mixed up. Goodness, he was out of his mind. I just wanted to find a way to.. to… um..get through to him. I wanted him to know I would be there for him and do whatever I needed to do to make him better. It was horrible to watch him come undone. I don't think I have ever felt helpless.* (Frank)

Sometimes the parent caregivers' efforts are inadequate to stem the tide of an illness episode or prevent a relapse of psychosis. They too often feel like failures. Sometimes the parents express feelings consistent with being stuck in reverse. They shared stories of trying to regain their own strength because they could not abandon their responsibility to their loved adult child. There were stories of stunning reversals of their young adults' life achievements. However, they lovingly journey on to make the best of things, trying if they can to "fix' their young adult child. Parents seemed to have an inner sense of duty, which gave rise to feelings of guilt when they felt they had insufficient energy to respond to their ill young adult.

Fix is from the Latin word *fixer,* which means to repair or mend and put into good condition. Parents “will stop at nothing” waging a long battle with the dragon to make sure their loved one has the best opportunity for recovery possibilities. For parents, the motivation to fix” their young adult appears to motivate a multitude of love-filled actions. Heidegger (1927/1962) says that care constitutes all of our involvement in the world and that there are two forms of caring. One form of caring “*leaps in*”; it can foster dependency and lead to domination. The other kind of care “*leaps ahead*” and cares for the other so that his or her potential for being remains open; this kind of caring focuses upon the person and his or her possibilities, not on the *task at hand*. One such action is for caregiving parents to leap ahead and advocate through ongoing vigilance to make sure that their young adult receives good care, from those described as “the best”. Even when it may be tempting to “leap in” and take over, caregivers consistently try to keep future possibilities open by leaping ahead (Ewing, as cited in Johnston & Scholler-Jaquish, 2007). Perhaps this is not surprising, but as a nurse who has formerly been the one who welcomed parents into partnership with an early intervention team, I was surprised at all the behind-the-scenes maneuvering that parents employed to make sure that their loved one was being cared for by the right people. Many of the parents had the inclination to seek help from their family physician or the emergency room but were not particularly trusting of the mental healthcare system. In parents' eyes, this was not considered "a soft place to seek refuge" from the distress of emergent psychosis. In reality it was the opposite: a desire to avoid if at all possible delivering a loved young adult into the wrong hands. This effort to avoid the wrong hands, involved all kinds of research in seeking the right place, the place that could be trusted to protect future outcomes. Most often the Internet was the source of research. Other parents sought consultations from friends who had previous experience with the system. A few others sought assistance from a self-help organization like the Schizophrenia Society. Thomas described the veracity of his wife as "just like a Sherman tank".

> *Anyway, one thing led to another and we talked to ah, in our church to a family who had a son who has a similar problem and he went to (the program). So then my wife who's like a Sherman tank, she's unstoppable. She pulled out all the stops to get our son to the program*. (Thomas)

The bold visual image of a "Sherman tank" is interesting to conjure up. A Sherman tank is a large American tank that was used exclusively in World War II. Its claim to fame was its ability to fire with reasonable accuracy when the tank was on the move. It was accurate, reliable and durable in the face of dangerous gun battles. Thomas perceived his wife to be just like a Sherman tank and it is clear that he saw her as a formidable force. She was described this way several times within his conversation. There is a sense that parent caregivers' leap ahead with their "big guns" loaded for this battle.

> *And like I said to my wife she's like a Sherman tank, she doesn't give up. So she phones and she talks and she writes and she calls and she does everything possible to get to the bottom of it come hell or high water.* (Thomas)

I had the pleasure of conversing with a large proportion of "Sherman tank*"* parents during this inquiry. By this, I am referring to parents who were prepared to "pull out all the stops", "stop at nothing", "to get to the bottom of things", "to keep up the battle", "to make certain of safety", "to do whatever I can", "through hell or high water", "to fix things". The young adult with emergent psychosis symbolizes the failure of Western culture to overcome nature. Even though we have treatment medications and strict diagnostic criteria and best practice guidelines at our disposal, we have not and cannot conquer nature. In our culture, we strive to become an ideal self: one who is fit, productive and economically independent (Callahan, 1993). Our culture ascribes little worth to the sick or the indigent. The medical subculture further upholds these notions of the ideal self by using medical technology to fight a war against disabling mental illness. Is it any wonder that parent caregivers hold the impression that is it unacceptable for their young adult children to be mentally ill? They seek on behalf of their young adult child every possible opportunity to enhance his or her recovery. Levinas (1990) stated that we cannot rid ourselves of such responsibility, because no one can take our place. In other words, it is our duty as humans, (especially as parents) to alleviate the suffering of others. Parents certainly held to this duty to alleviate their young adult's perceived suffering.

Breaking at the cracks

Sometimes all of this fixing is exhausting and leaves parents feeling like they are on the edge of "cracking up." Sharon wonders how much more she can take:

> *I was so stressed out. To be honest with you and I'm being totally honest I wanted an end to this. I didn't know how much longer I could take. Honestly I, you know, when she was talking about moving out in the back of my mind I thought oh maybe I won't have to go through this, but then you know my rational side goes well, No, she's, she can't, she didn't have any money and… Anyway, um, there was a point in myself that um, she was just driving me crazy. I was cracking up* (Sharon)

I think most of us in the human family might recollect times in their lives when they have felt like they would break, or crack under the pressure of something threatening or anxiety provoking. Colby Caillat, is a pop singer who has written a haunting song about times when we feel like we will crack up. Her lyrics capture this feeling of being overwhelmed, exhausted by the demands of life and wondering how best to carry on. This song is called *Breaking at The Cracks.*

Cause right now I am hurting all over again
And I never thought that I'd be in this place, is this a mistake?
And now I don't know how much more that I can take
I'm breaking at the cracks and everything goes black

It's another heart attack and I can't handle that

Whoa, love I need you back…

Colby Caillat

There is something so meaningful about the description of “breaking at the cracks”. First, I am reminded in a concrete way of an egg and how very fragile it is. Eggs are in fact so fragile that they are afforded special packaging, which hugs and fully surrounds each individual egg. Then the whole dozen are placed carefully amongst our other groceries to make sure they arrive at home whole and intact. Eggs are also used as “pretend babies” by teachers conducting experiential parenting lessons for high school students. At least, we used eggs back in my day. I understand that there are special high tech dolls, which are used for this purpose now. Seemingly, the purpose is the same, to have the high school students’ care, as a parent would do so, for an egg or a high tech doll. The point is obvious. Babies are fragile and care must be taken to protect them from harm and to keep them safe. It is a clear message that we send within our culture. We will work diligently at all moments to keep our children whole, and un-cracked. We put these expectations on parents and they incorporate this understanding into their role. Parents enact this role to the best of their ability and to the point of their own exhaustion. Parents sacrifice their own health and happiness to keep their children whole. Harold describes his experience of breaking at the cracks.

> *I was struggling to keep my own head above water. I had to take time off work. I got depressed myself. It was impossible to keep up appearances*

> *and be social with others. I withdrew. I had to stay close to home and fight my own desire to sleep until all this stress was over. It was completely exhausting everyday.* (Harold)

Logstrup (1956/1992) notes that it is through love that the other person becomes a living part of our own life. People connect to each other in love, sympathy and solidarity. The duties born out of a natural love, like that which exists between a parent and an ill adult child, requires attention to the shared spaces between them.

Worry Weary Warriors

Parent caregivers are at significant risk of "breaking at the cracks" themselves. Again, the notion of time comes into play here. The length of time before the young adult comes into treatment is often quite lengthy. Parents often described several years to many months of concerned attention, before arriving in an appropriate treatment setting. Harold held worry for his son years before he developed psychosis. This early awareness that "something doesn't seem right" has most often been a time of incredible worry and anxiety, many sleepless nights, increasing frustration, arguments with a young adult in denial and family disagreements about what to do. Parents describe a cascade of negative events, which precede the ultimate defining moment of acknowledging psychosis. Parents arrive to the early intervention setting, already worry-weary warriors, exhausted and close to breaking at the cracks themselves. They are not just beginning the worry journey. Most often they have been within that worry world for a long time and they are not through it yet. Even in the face of what have been good recovery stories the worry future literally wears them down. Heidegger (1954/1993) suggests that we are dwellers. Dwelling is our way of being interconnected with one another through care. Dwelling means to remain in place and be brought to peace, free from harm or safeguarded from danger. By parent's dwelling with their young adult child with mental illness they come together to find a sense of peace. They soldier on dutifully even when they are themselves exhausted. They sacrifice their own health and happiness for their young adult. Their love is selfless and endures. According to Logstrup (1956/1992) through our love, the other person becomes a living part of our own life. Through our natural love and duty to the other, in this case the loved adult child, we are able to give fully. The duties of natural love do not coincide with the duties we perform for payment (Ohman, & Soderberg, 2004). Almost all the parent caregivers in this study had a strong sense of satisfaction in this role, despite their description of exhaustion or feelings of being overwhelmed. Parents were duty-bound by this natural love. Hannah describes this exhaustion.

> *I didn't know how I would to keep going. It was exhausting and so stressful. I was sleeping. I kept worrying about him. It was hard to think about anything else. We had been upset about him for a long time but we didn't know what to do. It was so hard to get the help we needed. I am still really tired. I am beyond weary. Even now, I don't sleep well. I am always on alert. I watch him closely. I want to be ready, in case things change. This whole thing really takes its toll*. (Hannah)

The parents are always pushing upstream, carefully selecting their steps over slippery stones to prevent a fall into the deeper water. When they land in the water, they paddle, they do the sidestroke, breaststroke or crawl and some even flip over and swim on their back, but sometimes all they can do is tread water. They do all this with love and consistently attempt to find better more secure footing for themselves and for their young adult. The journey involves slippery stones and they get to feeling “beyond weary” but they get up and hold firm to the path. As parents live in relation to their young adult child something calls them to provide care. Buber (1970) proposes that in order to be fully human requires encountering another; “the concentration and fusion into a whole being can never be accomplished by me, can never be accomplished without me. I require a You to become; becoming I, I say You. All actual life is an encounter” (p. 62).

Perceiving homelessness

Surprisingly, a psychotic illness in a young adult child evoked consistent expressions of parental worry and anxiety about possible future homelessness. This anxiety disclosed uncertainty. The understanding of those who are homeless within our culture is often associated with untreated mental illness and addiction. Within my own clinical experience this possibility is not a frequent outcome of good early intervention. Certainly none of the parent caregivers I conversed with had had the experience of their son or daughter living on the street. However this was a solemn concern vocalized by almost all the parents. This concern about their loved young adult child with psychosis having a home was a common thread, which constituted the parents experiences. The perception that mental illness leads to homelessness was a really frightening image for parents. The streets of large Southern Ontario cities have their share of homeless youth. It is a sad fact in a country as rich in resources as Canada. These are the most visible, yet invisible people in any large urban center. These homeless folks were seemingly invisible to the parent caregivers until their own son or daughter fell into psychotic illness. Parents commented upon a new awareness, an awakening within them to the fact that these homeless individuals were someone else's children. They described feeling significant and unsettling anxiety in the face of those they saw living on the streets. They were terrified that this could happen to their young adult. Merleau-Ponty (1962. p.79) said, "that one's body is one's point of view upon the world. Man's body is his natural access to the world. Sensation, sexuality, language, and speech are all expressions of our existence, and are constituted concretely, in a bodily reach towards the world." Anxiety then, that sense of feeling apprehensive, unsettled and ill at ease, is the parent's embodied response to the fear of their young adult becoming homeless. Their anxiety certainly suggests that the future held homelessness as one very concerning and aversive possibility.

Although Frank's son had recently completed a post secondary college diploma program and had a job interview pending, Frank's fears and anxiety were still just below the surface. Frank commented about the fear of homelessness several times in our conversation. Once about the simple recognition of the numbers of mentally ill persons living on the streets and then other comments made later in the conversation about how he was grateful that his son, at least for now, is content to continue living at home.

> *You know you see so many homeless people and that, and I think, the, the mental problems that a lot of them do have, I think that their family probably doesn't even know. Like if you're here and they're out in Vancouver or something, and end up homeless. A lot of them I'm sure, I mean people are homeless because they're homeless, but I think a lot of it is mental illness too. I am glad he still lives with us. We can keep an eye out for him. I don't think I could sleep at night if he was living downtown. I mean, it would kill me if we lost touch with him. He's a great kid.* (Frank)

Hannah, whose son has also achieved academic success and graduation since becoming ill, admitted to me that since her son has been diagnosed with bipolar illness her own understanding about homeless persons has changed. She too, believes that parental love and support has a role to play in preventing this devastating outcome.

> *Like, you just think differently. Like now, even when I see people that are homeless, I always think, you know what, they very well could be mentally ill, they're there for no reason other than maybe they didn't have a family that could support them, like it just makes you look at everything differently.* (Hannah)

Bonnie feels grateful that her son has had what she believes to be a "pretty good" recovery. She compares his progress to that of others that she encounters on the streets. Bonnie expresses appreciation that things could have been worse, but she also shares her fear of what she perceives to still be the worst possible future outcome. The very thought of her son becoming homeless, unemployed and alone terrifies her.

> *Yeah, and it terrifies me when I see some of them (homeless people) on the street, you know, … living there and they just don't work, you know because they're not able, then I just think well (her son) he's fortunate. You know, he's done so well. But then you know there's some like him living out there on the streets.* (Bonnie)

Bonnie is aware of the potential for those with mental illness to end up unemployed and living on the street. From my vantage point, given the favourable recovery and excellent employment history she describes her son having achieved, this is unlikely to be her son's experience, but she still raises this concern. Why is it that homelessness is so much a worry in the face of such excellent recovery outcomes?

In a recently published survey, called the *Dignity Project*, sponsored by the Salvation Army (May, 2011) and intended to educate Canadians about the consequences of poverty in our county, provides a unique look at how Canadians feel about the more than 150,000 homeless individuals living on the streets in the big cities across this county. In effect Canadians held negative views of those who are homeless. They assumed that most individuals living on the streets want to be there. Individuals who are homeless are in effect to blame for their circumstances and seen to be disposable members in our culture. These findings were interesting in light of parent caregivers' fears. Is it any wonder that parents hold a culturally held fear that their loved adult child would fall into such a despairing and stigmatizing situation?

Before Sharon's daughter was admitted to hospital the family had witnessed a dizzying array of what were considered "*odd and perplexing behaviours*." Sharon was often tearful in describing an exhausting journey to try to get her daughter to the right place to get help. Despite the fact that her daughter has also achieved a wonderful recovery that involves successful completion of another university degree and professional practicum, Sharon focused upon what it was like the night her young daughter took to the streets. She relives this frightening experience when her daughter was wandering on the streets of the downtown of a big city. She was very ill and experiencing symptoms of mania. Sharon recalls the terror of this particular night. Her daughter had been extremely disorganized and making some very impulsive decisions. Sharon recalls with a burst of tears how worried she was that she could have come that close to losing her daughter.

> *She was taking time off work and talking to strangers on the street in [the big city] and you know, and so I didn't know what she was doing …[tearful]…Because she was wandering the streets of [the big city] talking and meeting up with everybody on the streets, being irrational, not*

> *um, communicating with us when she should have been, so we were so worried for her safety.* (Sharon)

Sharon was very emotional when she recounted this frightening memory. She feared for her daughter's safety and vividly remembers the worry of that evening, recognizing that there might have been far less favorable outcomes. Although she did not say it overtly she clearly understood that her daughter had been vulnerable to street life and might not have been spared the experience of homelessness had the parents not been "lucky" enough to have found her.

Although homelessness is not a typical outcome following a first episode of psychosis, parent caregivers were painfully aware that the onset of mental illness put their young adult at potential risk for such an outcome. It is not an easy problem to solve, but it is made even more difficult by our cultural refusal to acknowledge or face these seemingly discarded individuals. It was a very solemn topic of conversation that came up spontaneously as parents recounted their stories and spoke of their fears for the future. To the parents, even though recovery outcomes from clinical research suggest more favorable outcomes, first episode psychosis heralds the perceived beginning of a less hopeful life. Underneath this fear of homelessness, parents are ultimately concerned about becoming estranged, separated from their loved adult child. Is it any wonder that parent caregivers with emergent psychosis become so worried about the potential for their loved adult child to spiral downward into homelessness. The statistics about those with mental illness that live on the street are frighteningly high. I can't imagine being able to sleep at night if I knew one of my own daughters was sleeping on the street. I also can't imagine them being caked in dirt, layered in ill-fitting, inadequately warm clothing and sleeping on a cardboard mattress. I can barely imagine my comfort-loving daughters camping in a tent let alone living without access to a blow dryer. Our sense of comfort changes so quickly when face to face with unspeakable adversity. Having no address is a serious barrier to recovery and the parent caregivers intuitively knew this. They are constantly on alert for any signs that might indicate a relapse that sparks an impulsive departure away from home and family. This is the most recent poster from the Canadian 'Raise the Roof' organization's public education campaign for homeless youth. We must all make eye contact to make this problem go away.

Figure 8.1

According to Heidegger (1927/1962), the understanding of *Being* is embodied in social processes, language, cultural conventions and historical understanding. Through our way of Being in the world we come to know. This a priori understanding is said to arise through one's everyday involvement in the *world*. The public education poster above speaks to what we have come to know about the individuals who live on the street. They hold less value than the discarded chair. The poster is a form of digital art and as such is another form a language. Heidegger (1960/1993) suggests that art brings something into *Being* from its essential source. Art then, grants a clearing where art and artist can be. Art is a way to create a place of expression. Heidegger states (1960/1993):

> The clearing, the open region, is not only free for brightness and darkness but also for resonance and echo, for sound and the diminishing of sound… The clearing is the open region for everything that becomes present and absent" (p. 383-384).

Art, like this poster is a form of language that opens up the possibility of thinking and communicating cultural understandings. Parent caregivers understand the risk of homelessness and hope to prevent this frightening possibility. Recognizing homelessness as a possibility for their young adult sons or daughters also suggests that parents fear the future. According to Nouwen (2005),

> The first and most obvious quality of a home is its intimacy…We express a longing for that intimate place that offers us a sense of belonging…the

> word love continues to carry with it a warm love and remains one of the most evocative symbols for happiness (p. 146-147).

Having a home is essential to life. Home is a lived space. Parents are holding hope for their young adult child to remain close to home and close to heart.

Trading Places

When you love someone, and that someone is beloved to you, it is very hard to see him or her suffer. At least this has been my experience when someone whom I hold very dear is hurting, emotionally or physically. This is even more the case when the Other, who is suffering is your child. There is a song by Canadian songwriter, Jann Arden that beautifully depicts this sense of sacrifice for the ones we love.

I've never seen this kind of love, The kind that won't wash away
And then leave you in the dark
I would die for you
Jann Arden

The love expressed by parents and the lengths they were prepared to go, to reduce their son or daughter's pain and suffering was striking. Austin (2003), in her published study on *First Love* suggests that the expression of "risking death" (p. 137) is the gauge or a yardstick measure of love . Although she was not referring to parental love, this notion of a yardstick is also fitting here in terms of the lengths parent caregiver's will go to honour the love they feel for their ill young adult child. I think I had not fully understood the depth of this selfless love before I was immersed in the conversations. I had to open myself up to what was unknown. Consequently, I was often literally dumbstruck by the number of parents who were motivated to trade places. Parents consistently expressed the desire to take on the pain, to embody the distressing symptoms, to be the ones to suffer instead of their children. They wanted to make things right, to fix things, if possible, but if this couldn't be, they held onto an almost fanciful wave-a-magic-wand-kind-of-wish to trade places.

Harold spoke at length about his wish. He wished that he were the one who was ill and not his son. He felt that his son was so young and had not had the opportunity to live the bountiful life he should be living. Harold wanted to give his son the gift of health and endless possibilities.

> *And when something like this happens to your son, yes, it is the last thing you would want to happen, you just wish you could like trade places, to have it happen to you and not to him. Absolutely, that is what I wish. He had his whole life ahead of him and now this. I wish it was me.* (Harold)

Bonnie expressed her wish this way.

> *So, I just wish I could just take it all away and make her better. I wish I could wave a magic wand or something and make me the ill one and not her. She is so young and it kills me to see her suffer this way. I suffer with her. I have lived my life, she is barely getting started.* (Bonnie)

Janet suggested another bodily sacrifice she was willing to make if it would help her son enhance recovery. She was contemplating ways to pay for the potential cost of a wished-for cure.

> *I don't care what it would cost but I'm willing to sell, you know, my kidney if it meant he would be well.* (Janet)

Expressions of love: whispering normal

Parents expressed love for their young adult son or daughter with emergent psychosis in many ways. The illness onset and the confusing symptoms experienced awakened parents to action and evoked a myriad of caring and compassionate responses. Several parents stopped work, opting to take leaves or quit their jobs altogether. They removed themselves from their usual employment to be more available to their recovering young adult. Others, unable to leave work wished that they could be more available. The thought of their ill young adult being alone and unsupervised was a strong motivator for this course of action. All parents described wanting to be more available, to actively maintain their relationship and to watch over their ill adult child. There were many concerns about "*being there*" and "*being available.*" Parents often spoke of their desire to reduce depressive symptoms in their young adult by engaging them in outings and activities that would "*give them a lift.*"

Thomas described an outing with his son, which was clearly intended to distract them both from all things illness. This car outing was an important shared symbolic adventure and a temporary escape to all things normal, all things minus illness.

> *He said "Dad, ah, I love driving out in the country". I said look, "why don't we take a day off here and just go bumming around and go out for breakfast, and go out for lunch, and go out for dinner and just drive around wherever we want to." We had a wonderful day together. [Smiling, through tears] We didn't talk about any of this stuff, it was just us, like normal, like old times. And it was great, and we both felt so good about it.* (Thomas)

Carole tells another similar story about being available to her daughter. She is painfully aware that her daughter's friendship circle has diminished since her illness onset and feels very sad about the loneliness her daughter now experiences. Carole makes being available to her daughter a priority. She sacrifices time with her husband for extra time with her daughter. She has tried to become a friend replacement to make things more normal.

> *You know, like, she needs a boyfriend, she needs to go out, be young, and have fun. It's, you know, I'm not any fun. (laughs) I try to be, but, it just, yeah, it's like (laughs), how do you like going to movies with your mother? Well she and I did go and see Eclipse, ah, last week. Yeah, last week my husband went away, down to Ohio, and um, I said, okay, find out what time the show's on, so we went to a 9:50 show. Like, what teenager wants to be at the show with her mother.* (Carole)

Bonnie's love shows in the daily telephone calls she has with her son. She is consistently on alert for signs of worrisome anxiety and depression within these phone conversations. She also encourages her son to return every weekend as his friendship circle is described as having "*left him behind*." She notes that most of his former friends are now married and are busy with their own family. Sadness and loneliness motivates Bonnie's always being available to her son and to help him experience normal.

> *And he was getting depressed, so he'd, you know, I'd invite him to be with us at home, always at home on weekends because that's where he feels comfortable, right. And we'd make him comfortable. We'd make him feel loved, and wanted because that's what he needs*. (Bonnie)

Parent caregivers are motivated to make things better, to add a little more normal to the first episode psychosis experience for their son or daughter. This also makes the parent feel better that they are doing something. They constantly flirt with ideas of how they can make things a little easier. Victoria's son had a lengthy history of troublesome behaviours and a history of substance use for several years before he came into treatment for psychosis. There were a troubling number of encounters with the legal system and disappointments with addiction treatments. Despite all the hardships endured by her son and by all the other members of the family, Victoria summarizes her loving approach this way. When it comes to your loved child you just don't give up on them. Victoria continues to hold the hope for her son.

> *Yeah and I think it, at the time you just, like you know, you just go through it together any way you can and you don't, you know, you don't, um, you know, you just don't give up*. (Victoria)

In this chapter, I summarized the fourth story of enduring parental love. It conveys the depth of commitment parent caregivers have towards the comfort and wellbeing of their young adult child with emergent psychosis. Parent caregivers are motivated out of enduring love and will do just about anything to reduce the suffering of their ill child and engage in countless activities to "fix" the problem. When these efforts are insufficient they engage in fanciful wave-a-magic-wand-kind-of-wishes to trade places if they could, to lay down their live for the life of their ill young adult. They are alert to any and all signs of relapse and are especially motivated out of a strongly held conviction that their adult children are vulnerable to potential homelessness. The poignant stories of parental love were compelling, and oftentimes evoked a lump in my throat kind of raw emotion that was impossible to conceal. I co-lived the experience of the enduring love of parents and felt humbled by their resilience in the face of their own suffering. Throughout this inquiry I journeyed along side the parents and was touched and awed by their love.

Next in Chapter nine, I share my reflections of the research process as I lived it. Finally in Chapter ten, I will discuss what I have come to know about the meaning of being a parent caregiver. I will also articulate some suggestions for future nursing practice and early intervention policy.

CHAPTER NINE

To understand is not to project oneself into the text; it is to receive an enlarged self from the apprehension of proposed worlds, which are the genuine object of interpretation. (Ricoeur, 1981, pp. 182-183)

Reflecting on the Pathways

Self- reflection

In this chapter, I articulate the research process as I lived it. This self-reflective text shares my personal journey and the insights I gleaned in becoming a phenomenological researcher, albeit still a novice. It includes descriptions of the oftentimes painful frustrations of making this transition from my formerly numbers-oriented quantitative research, which was eventually dubbed my "quantoid side", but it also describes the thrills and freedoms inherent in not only learning to synthesize phenomenological data but perhaps more importantly to begin to live life more phenomenologically. Both Munhall (1994) and van Manen (1990) speak to the transformative nature of becoming a phenomenologist. This concluding stage celebrates my becoming phenomenological, that is, assuming a phenomenological perspective in my life as a way of *Being* in the world in interaction with self and others. The later part of this chapter will comment upon my using the Pathways and the Hermeneutic Principles for Research as articulated by Conroy (2001; 2003).

My introduction to *Being* phenomenological commenced during a doctoral level Nursing course. I took the course because I wanted to understand more about qualitative research and from a pragmatic perspective it both fit into my schedule and, through the wonders of e-learning technologies was available as a distance course. I was not at all certain what I was about to learn and began to get cold feet when I read the syllabus provided by Dr. Conroy (2006). The syllabus came with some photographs and graphics, some brief personal anecdotes from Dr. Conroy and a suggestion to read *The Red Tent,* a novel by Anita Diament (2007). Of course I read the novel right away but even after its completion was wondering in concrete terms what the story of Dinah had to do with my next nursing course? I was not sure what I was getting into. However, it was a process of determined unfolding, of undoing my thoughts about a singular truth and entertaining the possibility of multiple truths and perspectives. It was about abruptly departing from the concepts of pure science with its zeal for absolute answers and instead inviting alternate notions of truth and ways of being. Each course session invited our small group of students, to look at ordinary daily life experiences anew. Through several writing efforts we rediscovered the meaning of "A nursing, How are you?" (Cameron, 2004), and a "Bath". The small class group was a safe place to try on the phenomenological view and to embrace the fact that this attitude could help us to more fully understand what it meant to be human and the possibility to not only become better nurses but to achieve, if possible, greater humanness. The power of transformation in these thirteen weeks was extraordinary. I affirmed my previous notion of moving away from reductionist science and learned to embrace interpretive human science as a way to enhance my own abilities to understand others with care and compassion. This was a personal journey and by the end I was energized and ignited by new ways of understanding human beings. I immersed myself in all things phenomenological and practiced seeing things in a phenomenological way.

As much as I embraced this new perspective, I was also acutely aware of how the notions of traditional science and the current focus upon quantitative methods seemed to be at the forefront of our profession. I found myself living in two nursing worlds simultaneously. One was the world of evidence-based nursing, which given that I teach within the collaborative McMaster University nursing program, (the Canadian birthplace of evidence-based-everything), is still a substantial focus of my practice. The other world was that of attending to the meaning of human experience. In many respects the world of phenomenological understanding filled a void left by attending too intently upon finding perfect answers to clinical research questions. I certainly do not mean to criticize positivist science. Our profession owes much to the many nursing scientists who have helped and who continue to help us understand and shape good practice. I applaud what we can now call an abundance of nursing knowledge. However, I am suggesting that we embrace a fuller understanding of what it means to be human. This is simply not the kind of knowledge that comes from the scientific method. It is the kind of understanding one can glean from phenomenology. Human beings are non-reducible, experiencing subjects characterized by freedom, choice and responsibility (Watson, 1985). Nursing as a profession must allow for knowledge that comes from aesthetics, ethics, intuition and process discovery. Following completion of my this doctoral nursing course, I consciously endeavoured to live my life phenomenologically, which I must say again, is never easy. It encompasses my situated context and I am forever trying to move beyond my own assumptions and to be present to what is there and even attending to what is not there (Munhall, 1994; 2007; 2012). But I have also come to understand that the outcome of a phenomenological stance is liberating and has brought me much closer to the person, or at least to the nurse I hope to be. Over several years these experiences have transformed me.

Munhall (1994) notes that in integrating the philosophical tenets of phenomenology, “we become unknowing, learn to listen with a third ear, welcome new and different interpretations of reality, search for meaning of experience for self and others, and without assumptions, we become more understanding, empathic, authentic and compassionate” (p. 22). I would most certainly agree with this. Further, this is what my research inquiry aimed to do. I did not expect to change the world but I do hope that I have offered an interpretation of the experience of parent caregivers of young adults with emergent psychosis. I confess I have had to repeatedly remind myself of this aim whenever I felt I was losing some of my zeal to return again and again and again to the stories as told to me. I had to “unknow” the sense of steps, the sense of the comfort within a step-wise research method and find a way to be within the hermeneutic circle of understanding. I had to trust myself with the responsibility of being the voice of my participants and to capture their experiences. This was as much an exercise in affirming my own skills and strengths as it was to acknowledge the multiple skills and strengths I admired in others. I had to make sure that I was not privileging my own opinions and prejudices, rather being true to what was there in the language of the stories shared with me.

Meeting parents

As I approached each of the conversations with the parents, I was excited to be going back to the clinical setting. As I drove into the parking lot that first day, I sensed the dawn of a new phase in my research life but also in my life generally. I was impatient to get started. I felt a sense of urgency, to get to my destination and begin my research, a journey that had both informally been conceived and formally commenced through my studies at University of Alberta five years ago.

For me, the dialogical role of listening to and responding to the stories of moms and dads was a well-honed clinical skill but to have the honour of conversing with the moms and dads in a research context meant so much to me. I knew I was privileged to hear the stories from individual fathers and mothers. I admired their courage in sharing their perspective, on what it is like to have a young adult child with first episode psychosis.

Moving away from my former clinical role, I needed to experience the parents anew and be open to a new world of possibilities and meanings. The Heideggerian philosophy, which underpinned this research, confirmed the notion that we are already here living our ordinary everyday life (Heidegger, 1927/1969). Certainly, from the perspective of my ordinary everyday life I brought my former clinical skills and thirty years of nursing expertise to this research. I also brought my personal experience of having a loved one with mental illness. I know from both my first hand experiences and witnessing the experiences of other family members that caregiving for and protecting a loved one with emergent psychotic illness is a formidable task. This experience is far from the ordinary of the everyday. I needed to listen attentively and invite parent respondents to provide thick descriptions of their caregiving experience.

Stumbling along: one concrete step at a time.

Each time I entered into conversation with a parent I was amazed at their candor in sharing their experiences and even more humbled at their choice to share them with me. I also felt a responsibility to honour these stories and engage in phenomenological writing that honestly reflected the experiences as lived by each participant. Initially it pained me to abbreviate any portions of their stories for fear it no longer reflected what they wished to express. I frequently experienced a sense of responsibility or burden in trying to fully respect the parent stories in order to understand them in an authentic manner. I felt particularly anxious at this juncture and I am discomfited to admit that I attempted to return to what I knew of nursing science. I reverted to try to find the ‘right steps’. I tried to use a combination of Conroy’s Pathways (2003) in a stepwise linear fashion to complete the preliminary synthesis of the transcribed stories. It was just not as freeing or as liberating as I had envisioned.

The challenge of writing phenomenologically

The phenomenological writing involved in this research endeavour was a daunting task, and much more difficult than I suspected. Only through months of living with the data and throughout the concurrent writing and rewriting did I come to more fully understand the spiraling process. I needed to step off of the concrete research path. I needed to go where there was no path, to break new ground. I knew that I was being called to understand the irreducibility of human beings. I needed to abandon any notion of orderly steps and to embrace varied meanings and interpretations.

Writing, Rewriting and Learning to Fly

When in the midst of the early writing and re-writing process, the results of my computer writing were essentially pale and rather incipient versions of what I was feeling and experiencing during the deeply emotive and touching conversations. Somehow, whenever I sat down to write, once faced with the coldness of the keyboard and the distracting clickity-click noise of my fingertips as they hit the selected keys, the uninviting blankness of an empty electronic page on the computer screen, defied the expression of the tender and poignant stories of the moms and dads I had come to know. In some ineffable way the use of the computer technology interfered with the fullness of expression, belied the messiness of real life, as well as the circular and spiraling nature of subsequent interpretations of the meaning of first episode psychosis within the parent caregiving experience. The use of technology in the form of a computer screen and word processing software created a distance between the textual data and the flow and intimacy of phenomenological writing.

Despite my original intent to complete all data synthesis and writing on the computer, for me, there were no electronic short cuts, no technologically expedient ways to fast track the process of seeking a full phenomenological understanding. Therefore, very early on in this interpretive process, I abandoned the notion of writing on computer and returned instead to the slower but somehow more intimate process of handwriting. I filled journal after journal, enjoying the dog-eared pages, and the velvet feeling softness of the pages after they were transformed by the parent stories. The numerous modes of my cursive writing and printing were the varied ways I prepared and synthesized the data. I lived with all the pages of typed transcripts that included untold numbers of journal entries and other less formal notes written ‘on the fly’ as thoughts came to me. It was an interesting but strangely chaotic process, which found me writing interpretive thoughts on napkins, post it notes, pay cheque envelopes and the like. I wrote it all down as moments of phenomenological thinking opened up to me. I never ventured far without one of my notebooks.

Initially, out of my own inexperience, I tried to interpret the conversation data in a rather stepwise fashion through writing and rewriting the narratives. This was frustrating and frankly unsuccessful. As time went on, I found myself increasingly living with the research. In the midst of some seemingly unrelated activity, like going for a walk, or listening to music, or driving the car, I found myself thinking, pondering, wondering and then incredulously understanding something in a new way. I experienced an abundance of what I would call "Ah Ha moments" which came to me. As Heidegger (1927/1969) would say I was already in the midst of the research confronting the possibilities while wrestling with alternate possibilities.

Guided by Conroy's Pathways

Although my original intentions were to rigidly follow the pathway notions of Conroy's Aspects, I came, through my own experiences to more fully comprehend that phenomenology could not be approached by completing preconceived steps. "One must live the experience, drawing from who one is and is becoming" (Smythe et al., 2007, p.1396). I certainly know thorough personal discussions with Dr. Conroy that she never suggested that the Aspects of the pathways were a linear process. In fact she clearly warned against such an approach. Upon personal reflection the step-wise approach was motivated by my own anxious inexperience and my desire to somehow definitively solve the mystery of the parent caregivers' experiences. I naively wanted to find the "right answers", and only through the process of reflection combined with patient mentorship from Dr. Conroy, came to understand that I would only ever be able to offer some thoughts that might open up more thinking and discussion. Mine would only ever be one interpretation that might, if all went well, invite future interpretation.

After several months of trying to think alongside the data, instead of within the hermeneutic circle/spiral, my initial findings were personally disappointing, essentially confirming my own understanding of the parent experience but not particularly providing any fresh insights. Discussing my approach to synthesis with Dr. Conroy helped to really open up the interpretive spiral. While speaking with her, and sharing my tentative thoughts about my initial findings, I came to understand that I needed to free myself from what I already knew. I needed to be open to fresh insights that might emerge. I recall now with some amusement, Dr. Conroy saying emphatically, "You must let yourself fly". At first I resisted this suggestion, thinking to myself, "How can I fly and keep true to the Aspects on the pathway?" Then I understood on another level, that she was encouraging me to embrace the opportunity to make something visible, not simply from a linear, one dimensional time and space but from another, or even several other existentialist viewpoints. With my new insights and Dr. Conroy's prodding and support, I eventually gave myself permission to "fly", thus freeing myself from the notion of research steps.

As I have described, my first instincts were to find an orderly method of synthesis, but as I grew in skill and confidence, I was also concurrently aware that the way of my research must also "embrace Heidegger's understanding of *Dasein* as being there, being open, being in the play, going with what comes, and awaiting the moments of understanding" (Smythe et al., 2007. p.1392). When I reached this understanding I began to take flight, and to "Fly" as was so sensibly suggested. I certainly owe a debt to Dr. Conroy in helping me use her Pathway approach in a flexible way. I initially clung to the notion of preconceived research steps as the Aspects were described in written form as seemingly sequential steps.

This was a function of my own anxiety to “do things right”. Although Conroy’s Pathways (2003) represent six sequential Aspects or steps of the interpretive process, in reality it is an ongoing spiraling process, which is anything but linear. Dr. Conroy’s consistent mentorship became an important conduit for me to use her Pathways and Hermeneutic Principles of research as they were conceived and intended. Our relationship was an essential adjunct to my learning to engage fully and reflectively in interpretive inquiry. I admire Dr. Conroy’s endeavour to try to describe a process that is very difficult to truly represent in text.

Flying to New Heights

Dr. Conroy’s invitation to “Fly” led me to a deeper understanding of the meaning of the experience of caregiving parents when their young adult son or daughter had first episode psychosis. The metaphor of flying became my mantra and it prompted my liberation from my preconceived assumptions, legitimizing differences and striving to be emancipated from my former beliefs and stereotypes. I moved on from all things orderly and stepwise and instead embraced the back and forth and inside/outside notions of the hermeneutic circle/spiral. I genuinely learned to live phenomenologically. As a result I have begun to see the *world* differently. Indeed to study an experience you must live it (Munhall, 2007). I suppose that is inevitable. It is also something, which can be embraced and lived to the fullest or left to erupt in small unsettling ways with the hopes of catching ones’ attention. For instance, I found common threads between the experience of parent caregivers and my own experiences as a spouse of someone with mental illness. I know that each parent I conversed with had an effect upon me. They all touched me deeply and opened up alternate understandings of their experiences.

I consider it an honour to have had the chance to come to understand this group of parents. I will forever cherish the opportunity I have had to comprehend that authentic understanding of self and 'Other' is not only achievable, but honestly growth enhancing and empowering. Palmer (1998) says to be engaged in an eternal conversation about things that matter conducted with passion and discipline, truth is not so much the conclusions but the process of conversation, if you want to be in truth you have to be in conversation (p. 209). I humbly hope that the interpretations of these conversations might find themselves as the foundation of new sensitivity to parent caregivers and potentially enhance the supports and resources offered to them.

Considering limitations

As is the case with any research endeavour, this study has its limitations. As an interpretive phenomenological inquiry this study has specific limitations in regards to generalizability in the quantitative sense. Findings from this research are applicable only to the nine participants of the study as findings from a phenomenology study are the result of interaction between the researcher and the participants within a given context. Thus, it may be possible that others would perceive this work differently and present different insights or understandings. However, the findings may resonate with other parent caregivers of young adults with first episode psychosis. I have taken steps to acknowledge and explore the context in which the participants lived their experiences, remained as true to the original transcripts as possible, returned to participants for verification of their narratives, and offered interpretations that supported participants in their own unique experience.

The parent caregivers who agreed to participate were from the same urban area, which is served by a well-established early psychosis intervention program. They had all accessed the services and supports available to family members through this program. This translates into a collection of parent caregivers who had received a degree of support from professional caregivers throughout the time of emergent psychosis and early recovery of their young adult child. This may have served to provide a sample of parents who were more experienced in sharing their experiences. Also all of the participants indicated that they willingly took on the care of their young adult child. Thus, their caregiving experience may differ from parent caregivers who may feel more reluctant to provide care or do so out of obligation, not of love.

Despite the limitations to the present study, the parent participants and I were able to generate a rich interpretive understanding of the complex experience of parents' caregiving for a young adult child with first episode psychosis. In Chapter ten, I offer possibilities as to where practice and future research may lead in order to support parent caregivers.

CHAPTER TEN

So let us build with master art,
A bridge of faith between your life and mine
A bridge of tenderness and very near
A bridge of understanding, strong and fine
Till we have formed so many ties
There never will be room for walls to rise.
Author unknown

Bringing things together

This phenomenological inquiry was undertaken to offer an account of what it means for a parent caregiver to experience the emergent psychosis of their young adult son or daughter. The synthesis of findings provides new insights. Hopefully these insights will serve to inform further research and the subsequent development of pro-active and health promoting parent-supports. Through the lens of predominately Heideggerian philosophy, and having entered the hermeneutic spiral, I have come to a deeper and more thoughtful understanding of their *Being-in-the-world*. This process has certainly left me curious about how we come to endow experience with meaning. The nature of the meaning of the parent caregivers' experience led to uncovering four distinct stories, a story of Protection, a story of Loss, a story of Stigma and a final story of Enduring Love. The findings of this inquiry help to illuminate and bring awareness to what it means to be parents of a young adult child newly diagnosed with psychotic illness. In this concluding chapter, I illuminate how healthcare providers and nurses in particular can have more discretion, insight and discernment in clinical approaches with parent and family initiatives within the Early Psychosis Intervention (EPI) network. The findings of this inquiry may also serve to shape future policies, which recognize and affirm the strengths and resilient capacities of parent caregivers.

The gift of a glimpse into the parents' lifeworld

The nature of phenomenology is such that it provides a glimpse into experiences. Through conversations, participants of this study gave me entry into their "lifeworld" and generously allowed me such a glimpse. They openly shared their lived-experience through the stories they told about the emergence of psychotic illness in their young adult son or daughter. So now I must ask myself, what has been gained from this inquiry? Have I met the original aims of this inquiry? What if anything is of practical value in this text? Can this phenomenological knowledge inform nursing care and psychiatric practice, or health care policy? I concur with Munhall and Chenail (2008, p.60) who say, "we have a moral imperative to bring to light our findings".

In finding a fitting way to conclude this inquiry, and fulfill my moral imperative to bring the findings to light, I am left feeling an unsettling sense of wonder at the stories parents shared with me. I believe I will forever marvel at the power of parental love in the face of an adult child's suffering. For we are as Levinas (1985) says inexplicitly joined to those we love. In loving a young adult child with emergent psychosis, parent caregivers find themselves in a disrupted life, calling attention to the taken-for-granted, normally invisible boundaries of social relationships. Emergent psychotic illness makes demands on parents and causes them to turn towards finding ways to sustain their relationship with their ill young adult while maintaining their own health and wellbeing. This was true even when the young adult occasionally treated their parent caregivers with anger and distain, were threatening, even aggressive, denied that they were ill, disrupted usual family life, interfered with the expected coherence of everyday life, did things that were incomprehensible, distressing beyond measure, socially repugnant, or downright dangerous, it is love alone that pure and simply kept parents caring. This caring was most often selfless and aimed at restoring hope and enhancing the possibilities of the ill young adult.

This study helped to understand things anew. This was surprising to me in many ways. I previously worked with parent caregivers in an early intervention program and felt I had a fairly significant understanding of what it was like for parents when their young adult child became psychotic. I intuitively expected the parents in this inquiry to feel a sense of loss, to worry about the implications of stigma and to engage in protective behaviours towards their ill adult child. Although the initial themes that evolved were in keeping with my former intuitions, the meanings disclosed and uncovered within these stories were in many ways not expected. Through data synthesis in being repetitively exposed to the parent caregivers' challenges, I experienced them anew and at a different depth and most certainly with a new lens. I was often times moved, touched and thoroughly astonished by the findings. This was indeed a surprise. I found myself entangled in textual data which pointed to the ways that parent caregivers impose order, coherence and find meaning in a true life situation that often seemed incoherent, problematic and potentially imposed limitations on future possibilities.

Through phenomenological writing I have tried to interpret what that feels like for parent caregivers and acknowledge how this must be understood in the context of history and current social practices. Most gratifying, have been the opportunities I have had to ask my participants if I have captured their experiences. It has been most exciting when participants acknowledge that they have seen themselves within the writing and have understood their experiences differently as a result. I respectfully hope that my writing has done justice to their experience and that I have told stories that were previously untold.

Initially in synthesizing the textual data I often felt overwhelmed at hearing all the details of the parents' accounts. The stories I heard often astonished me because of their sheer poignancy, courage and the descriptions of the loving, tugging-at-the-heartstrings type of unfolding drama. I heard about the unimaginable pain and bewilderment of having to deliver a young adult child to a psychiatric care setting, or the horror of having to call the police on a loved adult child, the discomfort of having to live with the lingering guilt of thoughts that something you might or might not have done has lead to your loved young adult child's descent into mental illness. I was moved by descriptions of the terrifying fear that a late night telephone call could evoke, and the depth of the sorrow and accompanying worry that a bright and talented son or daughter may never realize a fraction of their potential and I often witnessed the "running-on-empty" kind of exhaustion that accompanies parental caregiving. The understanding of the meaning of these experiences came from within the relationships I established with the nine parent participants and their having trusted me to be respectful, and to show them and their ill young adults sensitivity and compassion. It is from this ethical stance that I offer the following concluding comments. My responsibility to them continued throughout the writing of this inquiry in my attempts to be faithful and thoughtful and to remain as close to the *world* of the parent caregivers as possible.

Drawing back the heavy velvet curtain

Parenting is often characterized by moments of epiphany, as if a heavy velvet curtain has been drawn, and with the benefit of more light, something is revealed more clearly. In the case of young adults with emergent mental illness there are most often months or even years before the curtain is drawn back far enough to bring the problem to light. The point at which their young adults' problem comes to light and is transformed into a disease by a declaration of diagnosis is an epiphany of sorts for parents. This epiphany however is a crystallizing moment, which has been most often avoided. The parents are pushed and pulled by social forces and a cultural history of abhorrence to those with mental illness. The extent to which parents' internal script includes notions of their having contributed to causation, seemingly has a substantial bearing on their openness to seek psychiatric treatment. I was surprised by the number of alternate hypotheses and professional consultations with clergy, addiction counselors, family therapists and psychologists that transpired prior to the young adult being eventually brought for psychiatric consultation. It appears that these former help-seeking efforts were deemed less stigmatizing and as a result more palatable.

Parents appear to act upon notions of right and wrong based upon culturally held values and beliefs. As Heidegger says we are born into a culture and it becomes a kind of blueprint for living. However there is no singular blueprint that guides the actions and reactions of parent caregivers. They listen to a pluralism of cultural voices dictating conflicting messages. Messages such as, ‘parents are to blame’, ‘parents are not to blame’, mental illness is not curable and always leads to a downward spiral of chronicity’, ‘mental illness is treatable and recovery is possible’ and ‘those with mental illness are a liability and unproductive members of a community’. These paradoxical cultural messages are magnified within a culture of capitalism that evaluates individuals on their ability to produce and contribute to profitable behaviours. So is delay in seeking psychiatric treatment really a surprise? I suspect that the long-held notions of mental illness and its stigmatizing nature ‘trickle down’ through cultural understandings and have a *significance* to parents, which lays silently underneath their choice of actions in response to emergent psychosis in their young adult child. The historical tendency has been to isolate those with mental illness. As was previously discussed in Chapter Two, those with mental illness have been exiled to hospitals with locked wards resembling prisons. The insane asylum remains the iconic cultural view of mental illness and prevents parents from openly discussing their mentally ill young adult.

Reinforcing re-conceptualizations of hope

As the chronicity of psychotic illness is the dominant conceptualization in our culture, nurses and other health care providers working with parents must help them re-conceptualize mental illness as highly treatable, and responsive to a combination of both psychotropic medications and cognitive behavioural therapies. This message was seemingly lost on the parents I conversed with. So herein lays the quandary. We have established specialized early intervention programs that serve to treat an emergent episode of psychosis early in the hope of protecting best possible prognostic outcomes, but we also have, strongly held cultural conceptualizations of chronicity. Knowingly delivering a young adult child into a care system with a socio-cultural history of hopelessness, possible homelessness and a substandard quality of life becomes repulsive to loving caring parents. They reluctantly engage in the care system provided for their young adult but they have trouble really hearing the hopeful messages provided by the clinical team involved with their son or daughter. Certainly the parents I met had been involved with a specialized early intervention team, and one would assume have been provided with current information and up to date evidence about prognosis. In fact most of the parents I met described their young adult's recovery accomplishments with palpable pride. Several young adults were described as living a rather unrestricted life after recovery from a psychotic illness. However, this was not the information that seemingly *mattered* to parent caregivers. In conversation with me it was the negative stigmas, the fear filled notions of chronicity and the worries about a less successful future that were consistently raised by almost all the parent caregivers. So having a specialized early intervention treatment program available to young adults with early psychosis does not substantially change the culturally held notions of mental illness. It is not the hope-filled place that healthcare providers strive to create. Secret keeping remains the norm. So how do we change the meaning of a first episode of psychosis? What possible interventions reassign meaning to an experience and infuse it with hope?

Finding the courage to share

It is difficult to know what it will take to change the meaning of this anxiety-engendering parental experience. The cultural understandings of parent caregivers are steeped in history and reinforced frequently in the media and in witnessing those who through inadequate treatment or untreated mental illness end up living on the street. However, as an interesting aside within my conversations with parents I became aware of something that seemed to really break down the notions of chronicity and replace these with a stellar example of a hoped-for recovery. As mentioned before it was a happy coincidence that a young female ‘Alumni’ of the early psychosis treatment program gave an inspiring public speech comprising the testimonial of her struggle with serious psychosis and her journey to recovery during the period of time I was first having conversations with parents. This event, which was coincidently attended by several of the caregivers I met, was a powerful and significant catalyst for changing notions of future possibilities. It surprised me that this singular testimonial of recovery had seemingly more impact than the educational support provided to the parents within the program setting or their own experience in witnessing the rather positive recovery journeys of their own son or daughter. I suspect that publically shared stories of more and more courageous young adult

“Alumni’, who by virtue of excellent early intervention achieve pleasing recoveries, and who will become part of the cultural understanding of mental illness such that these dated and erroneous assumptions of chronicity will eventually dissipate. For now, however, these assumptions remain a huge hurdle to overcome. I personally believe that encouraging the secret heroes among us to speak up about their illness experiences and recovery is an essential first step. Parents and their ill young adults need to feel secure in the notion that their reputations will not be permanently tarnished by the admission of mental illness. However, the negative consequences of public disclosure remain powerful deterrents. We need to help parents and other family members of those with mental illness to build bridges of faith between their life and ours.

Unwarranted notions of failure

Some of the most heart wrenching moments I spent with parent caregivers were ones where parents critically reviewed their parenting and found them self somehow complicit in their young adults illness. I was surprised by the extent to which parents held themselves responsible for the illness onset. We are living more than fifty years after the original theories of the schizophrenogenic family were popularized but the notion of parents as potential causal factors in serious mental illness remains. Diagnostic labels are imbued with history and still resonate with fear and apprehension. During the early moments, when parents receive the diagnostic proclamation, they generally hold the same unenlightened notions of schizophrenia or bipolar illness as others within our culture. It is imperative then, for nurses and other healthcare providers to provide moms and dads with useable explanations that assist them in thinking about themselves in a way that reduces self-reproach.

Again, generally this self-recrimination was not apparent on the surface of my conversations with parents. More often than not it lay hidden by social isolation and a physical distancing from other friends and family. They withdrew to review their parenting. Only in retrospect do patterns of understanding illness behaviour form. Could parents have guessed something was wrong earlier? Perhaps, but up until the point of psychiatric assessment, parents have been focused upon protecting their young adult child from negative outcomes. It takes a period of re-evaluation to reorganize their lives and hopes for the future in the face of a stigmatizing diagnosis of psychotic disorder. This also requires working through their feelings of guilt. Parents need to have time to review and discuss the whens, whys and hows of their experiences with their young adult child and microscopically view events that have taken place. Again the guilt is far more deeply felt than I would have imagined at first glance. It took repeated visits to the textual data and looking for what was not being said that shed light on this aspect of the parent caregiving experience. Parents hold themselves responsible for having somehow failed. The psychotic symptoms in their adult child are seen as the evidence of this assumed failure.

Nurses working with parent caregivers are very likely to miss the extent to which parents hold themselves responsible for having created mental illness in their child. Even though notions of schizophrenogenic parents have long ago been debunked, they still hold sway for present parent caregivers. Therefore, this needs to be explored openly with parents with the goal of evoking a level of self-forgiveness and personal affirmation. When parents put on the *inauthentic* brave smiling face while tears well up in their eyes, as I witnessed repetitively in my conversations, it invites a gentle and compassionate phenomenological uncovering. It appears that this self-forgiveness opens up new meanings of the illness and unleashes more active coping.

Each of the parents with whom I spoke entered the psychiatric care system in different ways. None were aware of where this entry would lead and none would have anticipated the extent to which they would be overwhelmed with a sense of failure and guilt. The parents I met were all making their own heroic attempts to put the emergent psychotic illness into a perspective that opened up possibilities for coping. They all struggled with ongoing concern for the health and wellbeing of their young adult and for themselves. Regret mixed with love and the wisdom of hindsight, permeated explanations of parents' coping. To be sure this emotionally laden struggle was further complicated and exacerbated by current understandings of chronicity.

Love-filled negotiations

The specific changes parents make in their daily lives to anticipate the present and future needs of their young adult with psychosis are negotiations made from enduring love. Sadness is especially likely to well up during conversations with healthcare providers when parents contemplate the future. The episode of psychosis has inadvertently changed the expected future. The reality of this change to the future is not as important as the perception of a more limited future. Parents are experiencing a profound sense of loss even in the face of good recovery outcomes. They are fearful that the future they once anticipated will not be realized or will take a very different form. They are afraid to hope for better. Parents fear that their hopes and dreams will be shattered. They live in a void of hope for fear of being disappointed again. This is rather perplexing given the accumulating evidence that a first episode of psychosis is no longer an invitation to a substandard life. Re-instilling hope becomes an important factor in working with parent caregivers. This places health care professionals in an uncomfortable position of articulating recovery possibilities without overstating the notions of cure. Encouraging false hopes can stand in the way of accepting the present, but not holding sufficient hope can guarantee the status quo and seriously limit possibilities.

Parent caregivers need help to envision undreamed of realities. Nurses have a moral responsibility to encourage parents to talk about their own realities. The focus of care in an early intervention setting is of course upon the ill young adult, but overtly recognizing that the needs of the parents who care for them are important too. They too are in pain. Their bearing witness to the suffering of their ill young adult brings about parallel parental experiences of suffering. It is too easy to become engulfed within the caregiving role and settle for a less joy-filled life. Just as a young adult needs help to see him or herself as more than a diagnostic label, parents must also embrace other life roles beyond that of caregiving. Nurses can help parents to see that caregiving is not one's whole life it is simply a part of that life.

Rewarding resilience

In a culture otherwise dedicated to individualism, parents often measure their morality through an ethic of care and willingness to subordinate self-interest to the greater good of the family. Parents in this study were often functioning in a selfless manner to provide care for their ill young adult. However, this selflessness often led to exhaustion and frustration. The question raised by this selflessness is an important one for healthcare policy makers. Just what is it that we expect of loving parents facing the onset of mental illness in their adult child? Can we build in supports for parents and supports for their ill adult child that embraces recovery and resilience for both?

The issue of finding suitable supports is particularly true for the mothers I met in my study. Parents' caring practices were seemingly gendered and fell to the mothers more so than the fathers. I suspect that women are disproportionately providing care for ill adult children and doing so while sometimes juggling the demands of working full time. I can easily see the value that parent caregiving provides to those who are recovering from a first episode of psychosis, but I also appreciate the value this adds to the specialized early psychosis teams. Parental efforts to care for an adult child with psychosis help the young adult to minimize potentially traumatizing hospitalizations and locate recovery efforts within a family setting. The efforts of parents to provide a maximal recovery setting is not adequately supported by policies that could prevent burnout, or at the very least appropriately acknowledge or compensate parents for their efforts. I suspect that parent caregivers are the best source of expertise with respect to their young adult's needs. This expertise needs to be incorporated into the overall recovery plan.

Embracing a different future

This study has uncovered what I consider an important number of issues that parent caregivers of those with emergent psychotic illness find challenging. This is especially important in working with parent caregivers within early intervention programs, as they are perceived of as "allies against a potentially severe but treatable mental illness" (Linszen & Birchwood, 2002, p. 271). Treatment within a specialized early psychosis program always involves education and support for parents. However the parents generally arrive with their own notions of mental illness and the meanings structured around their own background meanings and concerns impact the care they provide to their ill young adult. There is a gap between what enthusiastic early psychosis intervention clinicians understand about future possibilities for those with early psychotic illness and the more negative prognostic view of psychotic illness at least initially held by parent caregivers and is seemingly very slow to change. The parents do not have many role models to whom to look when the struggles of individuals who have achieved exemplary recovery outcomes generally keep their own experiences of psychosis a secret and they become the silent heroes in our communities. We need to know more about the meaning of disclosure and "coming out" for both young adults with first episode psychosis and their parents. We must also continue to grow in our understanding of parent caregiving in the contexts of history, cultural values and the immediate circumstances of their lives. As reality is something that humans consistently negotiate, recreate, alter and often disagree on, we need to consistently strive to update the perceptions of caregivers' realities. Despite a number of high profile anti-stigma campaigns, parent caregivers and the public at large are most influenced by the media. We must learn more about what forces exert changes to the public perceptions of those with mental illness. We must also learn more about the power and importance of hope to those with first episode psychosis and their families.

Graceful discernment

The first episode psychosis of a loved young adult child quickly transforms and returns parents anew into caregivers. The illness brings upon disruptive and worrisome changes to family life and the caregiving role is frightening and unfamiliar. Parents are catapulted into the foreign territory of the psychiatric care system. They are unfamiliar with the rhythm and structure of the system. They have many questions about the symptoms they have observed. They struggle to tease out the symptoms from their loved one's personality. They try to draw the boundaries between illness and demeanor or the angst and temperamental nature of adolescence. They answer all the questions posed to them. They are afraid. They are anxious about the diagnosis. They are frightened about the future. They are silenced by the stigma and they are utterly alone. They want to trust the clinical team but are uncertain about the suggestions being made.

They defer to expert opinion but fear the consequences of this action. They ride a roller coaster of cascading emotions and exhaust themselves with worry. They no longer know what to wish and hope for. They want this tossing and turning to stop so that they can catch their breath and get some rest. The diagnosis, while for some may be a relief at first, brings a new awareness that life as was known has changed forever. There will be a new normal and a new focus of parenting. The realization of new worries about medications and treatment approaches are dizzying and the scary realization of a possible forever-illness without a cure weighs heavily.

The potential for loss and shattered dreams heightens. The self-review of their parenting raises questions about possible wrongdoings, things missed, things overlooked. Through all this, the isolation increases and future hopes are held in abeyance. They think with their heart and respond to their young adult's suffering with a commitment to become warriors in this fight. They stay strong on the outside yet quiver inside. They resolve to do whatever needs to be done. They put their own needs aside and resolve to be there for their young adult child. They extend parenting duty beyond the norm and they feel weary and fatigued. They remain silent and alone. They modulate their hopes. They live with secrets. They feel ashamed, certainly stigmatized and yet their broken hearts still love unconditionally. Love literally hurts and parents give their love until it hurts. So what helps? Given what I now know and understand, how can nurses and other healthcare providers respond to parent caregivers in a meaningful and caring way? Perhaps more imprtantly we need to be aware of the possibility of this kind of selfless love being exploited by care systems which fail to recognise the impact of a young adult child with psychosis as having the potential to disrupt family life and exhaust the good will and intentions of loving parents.

Throughout this inquiry I reflected upon the experiences of parent caregivers and have learned much from them. I have felt and understood their pain, experienced their suffering and uncovered the meaning of a first episode of psychosis to parents who care. In fact what I have learned has transformed my thoughts about the kinds of nursing interventions and supports that would best meet their needs. Originally, before I commenced this inquiry I thought that perhaps group interventions might be helpful to provide support and education to caregivers. However, in coming to a greater understanding of the withdrawal and isolation that accompanies the initial phase of caregiving and the palpable shame and fear of stigma, group interventions as first steps, seem much less appropriate. I suspect that group intervention would create more distress for parents. In fact, I now believe group approaches are better second or third stage supports. Early on in this caregiving journey, parents appear to need time to acclimatize to the caregiving role, come to terms with what this diagnosis means for their ill young adult and then what it means for them. The turtle-hood of this early stage of caregiving makes group interventions less viable or potentially even unhelpful. Support at this time appears to best fit within an individual modality where skilled clinicians can meet the caregivers needs as they unfold and customize interventions both in terms of support and educational information sharing to their specific family context and significant concerns. This is far from a ‘one approach fits all' scenario. Understanding this, also invokes a warning that health care settings that only provide group supports for family members may want to rethink this as a singular family focused strategy.

Perhaps the most important implication of this research is the need for nurses and other health care professionals to enter into a caring relationship with each parent caregiver. As Levinas (1985) suggests, when we encounter a face we are responsible for that person. Being responsible for parent caregivers of a young adult with first episode psychosis means being present and really listening intently to what they are saying, but perhaps more importantly to what they are not able to say. This involves looking beyond the surface of dialogue to seek its meaning and to more fully expose the silences to understand what matters to parents. We need to engage in authentic dialogue and relationships with parents in order to help them (Austin, Bergum & Dossetor, 2003; Gadow, 1994). I understand that the therapeutic relationship between nurses and those they serve is foundational to the delivery of safe and ethical mental health care. In my mind it is the embodied experience of relationship that is the real instrument of healing and transformation. Recognizing that parents engaged with early intervention programs have no prior experiences with the mental health care system, it seems especially important that relational ethics form the values and ideals of a fully humane system of care provision (Hamilton Wilson, 2009). This presents a special opportunity to develop relationships with parents where nurses are fully present and committed to "attend to our collective responsibility in a shared existence both with and for one another" (Gadamer, 1996, p. 82). This will require that early psychosis practitioners nurture authentic dialogue with parent caregivers. This means taking the time to listen to parents' stories, which include their fears about guilt, blame, stigma and their worries about the present and the future in a non-judgmental way. This requires developing a trusting relationship. Trust is essential in creating the therapeutic space that nurtures honesty. Within such a relationship nurses can assist parents to identify resilience-enhancing coping strategies. This caring relationship will be one of the modalities to break down the isolation of the caregiving experience and give parents an opportunity to practice self-disclosure and self-affirmation.

In closing I must once again comment upon the extraordinary reservoir of love that seems to hold parents and their ill young adults together. The love and caring I witnessed throughout the months of this inquiry went deeper and touched me more deeply than I had expected. It seems that the habits of a parent's heart are entwined by a faithful love that is resilient and even withstands significant stress, illness and stigma. I will end this inquiry using the words of Canadian singer and songwriter, Bryan Adams.

When you love someone- you'll sacrifice

You'd give it all you got and you won't think twice

You'd risk it all-no matter what may come

You'll shoot the moon- put out the sun

When you love someone Bryan Adams (1997)

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APPENDICES

Appendix A: Glossary Of Heideggerian Terms and Philosophy as cited in Conroy (2001)

Anxiety:

that which gives cause to pause, that which causes a disturbance to everyday existence. It is caused by what is of significance to a human, who is startled, being challenged, threatened, puzzled or confused resulting in what is significant to be more accessible in the background. Anxiety is a special form of disturbance that faces us with a demand to own up to our lives (authenticity) or to get lost in inauthenticity or to remain in an undifferentiated existence. It can show up primordially the everyday state of mind of a person (modes of existence). It points to what is significant to a person; it provokes movement within the mode of engagement with the world

Authenticity:

one lives up to what one feels to be significant even if it is at odds with what is socially acceptable.

Authentic:

genuineness; living with eustress (positive stress); lives up to what one believes

Background :

the 'place' where mindless everyday coping skills, discriminations and practices, into which we are socialized, are situated; we use our everyday coping skills or 'tools' without mental representations; a web of relations of the tools with purposes assigned to them by persons; "practices are an aspect of an aspect of our everyday transparent ways of coping" (Dreyfus, p. 75); in the Background we engage in 'silent thought'. What is most significant in our lives is not easily accessible to reflection - it is not visible to intentionality

Background Meaning:

a web of relations in which something becomes intelligible through interpretation; discovered through the hermeneutic task of interpretation or the fore-structure

Being:

‘Human being’; refers fundamentally to intelligibility; a human is self-interpreting; necessarily involved in and dependent upon the world; amid a world of shared meanings and understandings in the social context; mode of being human which must exist factically. A person is never settled in the ‘world’, never clear about the ‘world’ in which one finds oneself. Steiner provides useful metaphors to explain Heidegger’s human being such as: Being as a suppressed echo; Being as similar to the moments of experience and ineffability in music, where even the intervals have meaning. “In music, being and meaning are inextricable. They deny paraphrase. But they are, and our experience of this “essentiality” is as certain as any in human awareness” (1992, p. 43).

Being-in-the-world:

a specific form of existence which emerges into presence in reciprocal interdependence with other Beings

Care:

engrossment with the Other; the moral agent is in concert with the Other, with intention ‘Other-directed’.

Care-for:

necessitates a level of reciprocity between the one-caring and the one-care- for; task oriented (Shogan, 1988); tend-to another or to an object

Care-to:

unidirectional care given to where physical care is not augmented by reciprocity or mutuality; it is a care infused with doing-to; similar to care for .

Care-that:

to be motivated to bring something about; involves ‘caring about’ and ‘caring for’

Caring Practices:

Caring starts with reciprocity and includes several aspects: reciprocity, prescencing, particularity, mutuality, competence, intentionality, affectivity, intuition, sensitivity, gracefulness, connection, attending to the Other, compassion

Co-constitution:

persons form an integral part of a communal world, not as separate entities; the world and the individual co-constitute meanings or understandings;

Compassion:

“Taking a stand with others in their distress...takes seriously the reality of other persons, their inner lives, their emotions, as well as their external circumstances; an active dis0position toward fellowship and sharing, toward supportive companionship in distress or in woe (Bennett, 1993, p. 102); to feel another’s anguish; two dimensions of imaginative projection can occur: sympathy and empathy. Sympathy means to have the same feelings that the other has, not just to understand the feelings. Empathy includes objectivity which allows the helper to look at alternatives to their present situation. (see Berger and Williams). “Sympathy denotes agreement, whereas empathy denotes understanding and acceptance of the person...At its worst, sympathy is a form of collusion" (Egan, 1994, p. 120); ability to put oneself in the place and point of view of another; "to see one's neighbour as another self" (Bennett, 1993, p. 107). "Just as courage takes its stand by others in challenging situations, so compassion takes its stand with others in their distress. Compassion is a virtue that takes seriously the reality of other persons, their inner lives, their emotions, as well as their external circumstances. It is an active disposition toward fellowship and sharing, toward supportive companionship in distress or in woe" (Bennett, 1993, p. 107).

Concern:

A way in which one is available or engaged in dealings with others. This concern manipulates things and puts them to use when trying to understand the other people around us and move into some decisive involvement. It reflects onto our own way of being as well being of others. The world is experienced directly in terms of meaning for the self. It is transparent coping with equipment (concern) versus coping with people (solicitude)

Connectedness:

recognizes three fundamental aspects: (i) the essential particularities within a person's embodied self; (ii) we live a world of connected relationships, not as hermits nor as autocrats; and (iii) we live in a biological relationship with the world (Campbell, 1984). In contrast, distancing is manifested by: (i) viewing a person as split into mind separate from body; (ii) fostering dependency in another and viewing non-compliancy as deviant behaviour; and (iii) viewing humans as independent and superior objects in the natural world; seeing oneself as connected to other people in the world

Coping:

The kind of concern which manipulates things and puts them to good use; can occur in the Background in a mindless way, through a semi awareness when the usual ways of coping don't work through to occurrent modes of coping where coping becomes manifest and can be viewed objectively.

Courage:

“To be courageous is to be someone on whom reliance can be placed. Hence courage is an important ingredient in friendship” (MacIntyre, 1985, p. 123)

Embodied intelligence:

an understanding of a person embedded in a culture, a form of culture, a world’ of involvements’ (Taylor, 1993, p. 318). Shared, perceptually based common practices are incorporated and shown through the paradigm of the lived-body (Leonard, 1994). Body and mind are not separated rationalistically, but united holistically.

Empathy:

“Imaginative projection into another person’s situation, especially for vicarious capture of its emotional and motivational qualities” (Audi, p. 261). “A precondition of ethical thinking” Audi, p. 261.

Epistemology

‘Knowing that’ something is true; constructed way of knowing; consistent with Cartesian duality or mind/body split; abstract theoretical calculation

Factual:

the idea that facts exist independently of our being

Factiticity:

the idea that we are able to understand ourselves as bound up in our own as well as others’ destiny. We ‘dwell alongside other persons.

Fore-conception:

we grasp conceptually in advance the appropriate way to interpret something

Fore-having:

a general grasp of the whole situation we have in advance

Fore-meaning:

fore-having; fore-sensing

Fore-sight:

we see or sense in advance the appropriate way in which things can show themselves

Fore-structure;

involves temporality; an explicit understanding of the Background; involves fore-conception, fore-having, and foresight

Genuineness:

authentic; lack of sham or feign

Hermeneutical circle:

the circular form of interpretation shared between persons in their interactions

Hermeneutical spiral:

spiraling interpretation where the interpretations of a group of people build on each others' understandings over a period of time

Historicity:

Heidegger's notion that we have a past which forms our background (culture) which affects our present (an in many ways our future.

Inauthentic:

mode assumed by someone who actively adopts a way of doing something, even though the person does not necessarily value that way of being on the surface; covers one's genuine way of being; discord (distress) between what one says and what one does; we have lost ourselves in things and other persons while existing in the everyday world; although it is necessary to regard scientific things in this objective way in healthcare, inauthentic in a moral sense refers to regard of people as things to be used for one's own purposes.

Inauthentic:

habitual way of being inauthentic undifferentiated

Intentionality:

deliberate engrossment in nurturing the potential of the Other in all circumstances. a system of coping for ongoing purposes, as the 'toward-which', the 'for-sake-of', the 'in-order-to'. It is future oriented; conscious self-awareness; a deliberate thoughtfulness (Titchen, 2000, p. 93). Macmurray (1957) differentiates intention into theoretical intention and practical intention, although each are complementary to the other; i take non-philosophers' motivation to be equivalent to Heidegger's intention. In practical activity there is recognition of alternatives for action and the possibility of choice between them.

Joy

pleasure in ‘what-is-there’. The one-caring takes pleasure is meeting the Other, and in enabling the Other to reach his potential.

Lived experience

antonym to observed or vicarious experience; experience in which we are actively engaged with our whole Being

Modes of engagement;

ready-to-hand; unready-to-hand; present-at-hand

Mutuality

reciprocal and fundamental recognition of partnership in the caring relationship. It requires recognition by the one-cared-for that the practitioner has an expertise in providing competent care within his discipline and a recognition that the One-cared-for knows himself best. In deference to the Other and involved ‘significant others’, the one-caring allows room and time for sharing knowledge and for choice in solutions, rather than encouraging dependent behaviours. Empathy is a necessity in understanding. Comforting or compassion is a practical outcome of mutuality

Ontology:

‘Knowing how’; understandings of ways of being; embodied knowing

Particularity:

attending to what is contextually important to/for another individual. It opens the one-caring to surprises rather than to seeing only the sameness of what is universal in others. One can attend to the particularity of the embodied responses of the Other. The

Other's experience defines the limitations (and the possibilities) of her responses to situations where she requires assistance. Allows salient practice to flourish. Through "saliency, or knowing what is important, what matters, what is of concern and significance, from both the nurse's and the patient's perspectives" (Titchen, p.94), Particularity is similar in the practice of people who are open to the Other, what is of significance to them in the Heideggerian sense

Person:

Incorporates in moral agency the concept of culture (historicity), significance, present and future (temporality and intentionality), and lived experience (embodiment).

Prejudice:

stems from prejudgments governing our own understanding and that of others. It reveals one's own foregrounding and the appropriateness of one's own fore-meanings and prejudices. It is used within interpretation to reflect upon that which is under study. It is necessarily part of our interpretation of the world and joins in the hermeneutical circle with the understandings of Others; a fore-having. The term 'bias' is a pejorative form of prejudice

Preontological:

understanding which exists before one is born but into which we are socialized. "We dwell in the equipment, practices, and concerns in some domain without noticing them or trying to spell them out" (Dreyfus, p. 90). Cultural or preontological understanding reflects an apprehension of "How things in general can count [in our world] through being initiated into the practices and understandings of our culture" (Guindon, p.14).

Prereflective:

understandings which develop as we learn how to cope within the world; thought without language;

Present-at-hand:

mode of non-engagement with people, where entities are context-free; Cartesian duality of body/mind is the norm; context free engagement with the world; ahistorical understanding; mental representations; skilled scientific activity

Ready-to-hand:

seamless, transparent coping in the ‘background’ of the world. Can move gracefully in a relationship characterized by mutuality, reciprocity, particularity; characteristic of an engaged agent functioning with embodied intelligence

Receptivity:

a feeling or sentient mode where one ‘receives what is there’ through being engrossed in the situation. This engrossment requires that the one-caring clear her mind so as to be receptive to listening, looking, and feeling the moral dimensions. This opposes emotional entry into a situation such that one’s view is clouded by one’s own feelings.

Reciprocity:

a receptive exchange between Self and Other. “reciprocity includes responding both for our own sake and for the sake of the other, independent of our personal stake” (Kupfer as quoted in Johnson, 1993, p. 201). The responsibility of the Cared-for is to reveal oneself willingly although perhaps unconsciously (Noddings). A bond is formed between client and practitioner which involves negotiation, receiving, learning (Titchen). There is an alertness to openness; receiving allows the vulnerability of the one-caring to surface, i.e., one’s humanity and authenticity; includes responding both for our sown sake as well as the sake of the other, independent of our personal stake” (Kupfer)

Significance:

things which show up as mattering or counting in relation to our practical affairs. The for-the-sake-of which. Significance is “the background upon which entities can make sense and activities can have a point” (Dreyfus, p. 97). Of significance is what matters to a human. It directs our activity in a taken-for-granted, non-mental way towards the future, towards the ‘for-the-sake-of which’. Things which show up as mattering or counting in relation to our practical affairs.

Solicitude:

coping with people as opposed to coping with equipment (concern)

Task of hermeneutic

interpretation the fore-structure of understanding which functions at three levels: fore-having, fore-sight, fore-conception

Temporality:

Heidegger’s notion that our past and future projections or desires affect our present situation and choices

Undifferentiated:

a mode where one is lost in a world where one passively assumes a stance picked up from the public collective way of not taking charge of oneself; person goes uncritically ‘with the flow’; people exist in this mode most of the time; many of life’s activities happen while we are in this mode

Unready-to hand:

mode of engagement with the world which can be entered into conspicuously. Conspicuousness occurs when a person pauses, hesitates because unusual tools are needed - the old tools are not appropriate for the context. Obstinacy occurs when the distressing 'object' becomes manifest. Obtrusiveness occurs when there is a total breakdown in our usual coping methods. nothing 'works' the way it normally does for us. Activity is very apparent to us, and we turn to more theoretical reflection about how to cope

World:

the entire constellation of beliefs, values, assumptions, background meanings, possibilities, and cultural organization shared by the members of a given community. Heidegger deems the world of society to be always prior to one's own world (Dreyfus, 1993; Hall, 1993). The world of the student is the set of meaningful relationships, practices and language to which students are introduced upon entering the health sciences field of study (the present). It incorporates the world they have inhabited in the past. It is directed towards the future; a person can exist in three interdependent modes - authentic, inauthentic, undifferentiated; organised equipment and practices in which Being is involved

Appendix B: Letter to gain entry to Cleghorn EPI Program

UNIVERSITY OF
ALBERTA

Project Title: *First Episode Psychosis: The experience of parent caregivers*

Principal Investigators:

Sherrill Conroy, RN, D Phil, Assistant Professor, Faculty of Nursing, University of Alberta, phone: (780) 492-904, email address: sherrill.conroy@ualberta

Wendy Austin RN, PhD, Professor, Faculty of Nursing, University of Alberta, phone: (780) 492-5250 email address: wendy.austin@ualberta.ca

PhD Student Co-Investigator:

Jane Hamilton Wilson, RN, PhD(c), Faculty of Nursing, University of Alberta, phone: 519-748-5220 ext 3901,email address: jeh3@ualberta.ca

To: Dr. Suzanne Archie

Clinical Director, Hamilton, Ontario

Dear Suzanne,

As you are well aware, I am interested in learning more about the experience of parents in response to emergent psychosis in their youth or young adult son or daughter. I want to talk with mothers and fathers who have a son or daughter registered within the Cleghorn Program for a minimum of six months and a maximum of 36 months.

I am officially seeking your support to display an information poster about the study in a visible and easily accessible location at the Cleghorn Clinic. I will need occasional use of an office within the building but will not require any further use of any human or material resources. I will however need to prevail upon you to be the Local Principal Investigator to put this project through REB at McMaster University.

I have attached an information letter about this study to provide you with details about this research project. I also have attached a copy of the planned poster for your information and comments. I look forward to hearing from you. I would be happy to meet with you to discuss my research project in more detail. I can be reached at (519) 748-5220 X3901 or at jeh3@ualberta.ca

Yours Truly,

Jane Hamilton Wilson RN, MHSc, PhD(c), U of A.

Appendix C : Letter of REB Approval St. Josephs, Hamilton

St. Joseph's
Healthcare Hamilton
McMaster University

RESEARCH ETHICS BOARD

50 CHARLTON AVENUE EAST, HAMILTON, ONTARIO,
CANADA L8N 4A6

Tel. (905) 522-4941 ext. 33537 Fax: (905) 521-6092

Dr. Suzanne Archie

The Cleghorn Program

703 - 25 Charlton Ave. E.

Hamilton

Ontario Canada

RE: R.P.#09-3273

Study Title: First episode of psychosis: the experience of parents

Local Principal Investigator: Dr. Suzanne Archie

Received date: 01 December, 2009

Review type: Expedited

Initial Approval: 18 December, 2009

All Received Enclosures:

Application Form - General Research Application

Protocol - Protocol ver: 1 03 October, 2009

Information Letter to Participants - Appendix C: Information Letter

Recruitment Material Other - Participant Screening Form

Dr. S. Archie
December 18, 2009

RE: R.P. #09-3273

Information Letter to Participants - Appendix E: Information Letter

Consent Form (Main) - Appendix F: Informed Consent

Other - Consent for Disclosure of Information

Other - Appendix H - Field Notes

Other - Appendix K - List of Available Supports and Resources

Other - Introduction to the conversations with parents

Dear Dr. Archie:

A member of the Research Ethics Board has reviewed R.P. #09-3273 on 15 December, 2009 and approved it subject to resolution of the following issues/conditions:

Application:

1. No TCPS tutorial attached as indicated – provide copy of TCPS or GCP certificate for local PI.
2. Application states approval from Universityof Alberta REB to follow - provide copy of approval letter.
3. Protocal indicates that all research documents, journals and audio files will be kept in a locked filing cabinet. for 7 years, whereas the application states the data will be kept 10 years - please clarify.

Protocol:

4. Submit a revised copy of the study protocol with the study title on the document, and with a date, version and page numbering on each page of the document in a footer.

Participant Screening Form:

5. State explicitly on the form at the beginning that this is a research study and that participants are being invited to participate in a research study being conducted by a PhD student.

Appendix C: Information Letter, Appendix E: Information Letter, Appendix F: Informed Consent, Consent for Disclosure of Information:

All forms need to be reformatted to meet SJHH standards:

6. add SJHH logo to top of forms;
7. add name of Local Principal Investigator;
8. assign a version date to each of the documents and place in the footer on each page of the document;
9. add page numbering in the footer for each document if it contains more than one page.
10. When submitting revised documents, remove “Appendix C – Information Letter”, etc… from top of forms.
11. Use a consistent size font for all text in the document, i.e. why are the names of the investigators printed in such a small font?

Appendix C: Information Letter:

12. Information Letter, Apprendix C has the principal investigators listed first then student co-investigator on other side of page…this is confusing when you read the information letter because within the body of the text it states, "I am looking for up to 10 participants" …letter may read better if the investigators are listed one after another and the text says "we" rather than "I".

Information Letter, Appendix E:

13. Form lists several investigators, however, it is written in the first person, i.e. “I will talk with you..”, etc.. suggest re-writing in third person, i.e. “we”.

14. 2nd paragraph under What will happen? the word "times" should be inserted after “one or two”.
15. Indicate that there is no benefit to the individual participant.
16. Page 2, contacts: Dr. Archie should be added to the list of contacts.

Information Letter, Appendix E/Appendix F: Informed Consent:

17. Suggest combining both documents into one with consecutive page numbering.

Appendix F: Informed Consent:

18. Add space for printed name of investigator or designee.
19. Add a statement to indicate that the participant will receive a signed copy of the form.
20. Add contact information for the SJHH REB re the participant’s rights as a research participant to the bottom of the form (suggested wording available from sample consent form on the SJHH REB web site).

Please forward your response to these conditions to the office of the REB in Room H307 for final approval before commencing your research.

Please note: your revised submission should include a cover letter which addresses each of the items identified in this letter and refers to each item number. An electronic copy of this letter can be provided if you wish to insert your response to each item directly on this letter. Please be sure to send the response to the REB in hardcopy, enclosing any revised documents. The revisions should be clearly highlighted in each revised document (provide a marked up copy and a “clean” copy of the new version). Please note that the version date must be updated each time a revised document is submitted to the REB. Upon receipt of the revised submission, final approval will be forthcoming if all conditions have been addressed.

Conditions must be met within 60 days of conditional approval or adequate reasons for an extended delay communicated to the REB in writing.

Please reference R.P. #09-3273 in any future correspondence.

Sincerely yours,

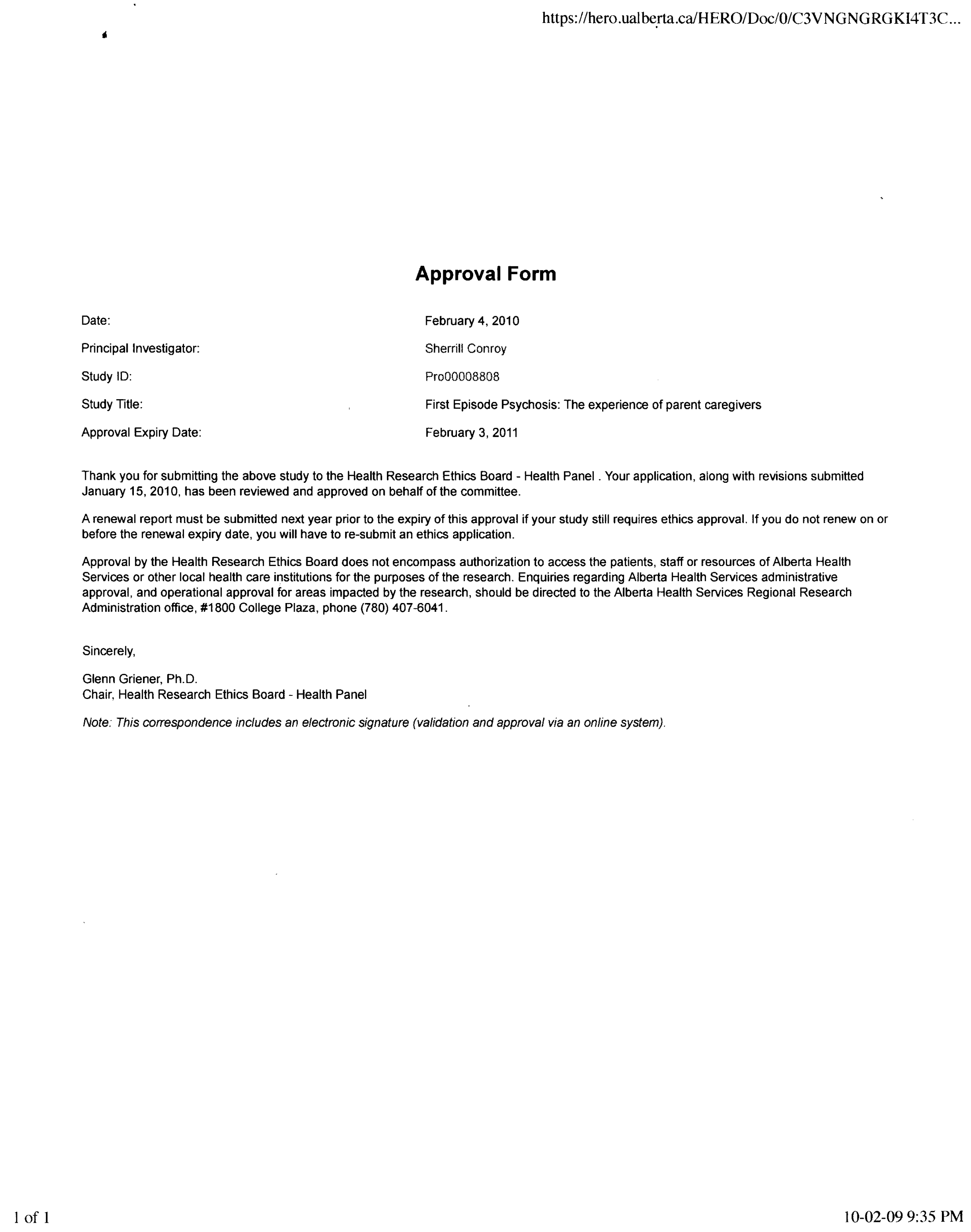
Raelene Rathbone, MB, BS, MD, PhD

Chairperson, Research Ethics Board

RR:lmm

.cc J. Hamilton Wilson

Appendix D: Approval from University of Alberta



https://hero.ualberta.ca/HERO/Doc/0/C3VNGNGRGKI4T3C...

Approval Form

Date:	February 4, 2010
Principal Investigator:	Sherrill Conroy
Study ID:	Pro00008808
Study Title:	First Episode Psychosis: The experience of parent caregivers
Approval Expiry Date:	February 3, 2011

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel . Your application, along with revisions submitted January 15, 2010, has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health Services administrative approval, and operational approval for areas impacted by the research, should be directed to the Alberta Health Services Regional Research Administration office, #1800 College Plaza, phone (780) 407-6041.

Sincerely,

Glenn Griener, Ph.D.
Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

1 of 1

10-02-09 9:35 PM

Appendix E– Sample Recruitment Poster

RESEARCH STUDY

Cleghorn Moms and Dads
Can You Help?

**Are you willing to talk about your caregiving experiences with your son or daughter?*

**Has your son or daughter been a Cleghorn client for 6 months -36 months?*

I would like to talk to you to about your experience of being a parent caregiver.

I am a nurse with more than 30 years experience in mental health settings and a doctoral student at the University of Alberta.

Please call to arrange a meeting.

Jane Hamilton Wilson RN, PhD candidate

519-748-5220 ext 3901

jeh3@ualberta.ca

Appendix F: Information Letter

St. Joseph's
Healthcare Hamilton

St. Joseph's Healthcare Hamilton
FEB 01 2010
Research Ethics Board

Project Title: *First Episode Psychosis: The experience of parent caregivers*

Local Investigator:

Dr. Suzanne Archie
703-25 Charlton Street
Hamilton, Ontario
(905) 540-6586
archies@mcmaster.ca

Principal Co-Investigators:

Dr. Sherrill Conroy RN, DPhil
Associate Professor, Faculty of Nursing,
University of Alberta, Edmonton
(780) 492-9043
sherrill.conroy@ualberta.ca

Dr. Wendy Austin, RN, PhD
Professor, Faculty of Nursing
University Of Alberta, Edmonton
(780) 492-5250
waustin@ualberta.ca

Student Researcher:

Jane Hamilton Wilson RN, PhD candidate
Graduate Student, Faculty Of Nursing,
University of Alberta, Edmonton
(519) 277-0243 or (519) 748-5220 X 3901
jeh3@ualberta.ca

Purpose: This study will look at the experiences of parents of children with a mental illness. The goal of this study is to understand more about the impact of this experience upon mothers and fathers.

Research Process: We will be looking for about ten parents to help with this study. The student researcher will meet with mothers and fathers individually once or if you wish a second time. Interviews will last about 60 to 90 minutes. Parents will be invited to share their story of what it is like to provide care for a son or daughter with first episode psychosis. Parents will be asked to share their thoughts, feelings and responses to the first psychosis experience.

Implications: This research aims to help parents and health professionals better understand the parent's experience of caring for a child with early psychosis. This research may also guide program practices at the organizational or policy level.

Supervision: This student research project will be co-supervised by Dr. S Conroy and Dr. W. Austin, Faculty of Nursing, University of Alberta, Edmonton, Alberta.

For more information, please contact:
Jane Hamilton Wilson RN, PhD candidate, Graduate Student,
University of Alberta
(519)748-5200 X 3901or (519) -277-0243
email: jeh3@ualberta.ca

Version 2: January 10, 2010

Appendix G – Participant Screening Tool

Date: ____________________________

Thank you for calling me to find out more about the parent caregiver study

How did you hear about the study?

____

I want to talk with Moms and Dads with a son or daughter who has been in the Cleghorn program for six to 36 months. Does this sound like a fit for you?

(IF No) I thank you for your time. I am looking to talk to parents at an earlier stage of parenting.

(IF Yes) Would you like to hear more about the study?

Can you please give me your initials

____

Contact Phone number:_______________________

Alternate number: ___________________

E-mail: _____________________

A bit more about the study:

Purpose:

- I want to know what parenting has been like for you since your son or daughter has been ill. I am interesting knowing more about this experience so that I can better understand what helps and does not help parents in your situation.

- You will not directly benefit from telling me about your experiences of parenting. You might even become upset as you tell me your story, but what you tell me may become helpful to people who plan programs to help other parents in your situation
- I will keep what you say private. Your name will never appear anywhere. Your words may be used but never your name. I will keep your personal information locked up.
- You can tell me at anytime that you do not want to answer a question and you won't have to. You can also tell me at anytime that you do not want to participate in the study anymore and we will stop immediately.

Are you interested in participating in the study? Yes_____ No ____

(you will be asked to sign a consent when you come to see me)

Address and Directions:

Clarify location of meeting and provide directions.

Scheduling of interview:

Date: __________________________

Time: _____________________________

Before we finish:

We will be telling your story of your parenting experiences since your son or daughter has been ill. It will take us about 90 minutes to have this first conversation. I will be taping the conversation and will give you a summary of our conversation. I would like to meet with you at least once.

Appendix H: Signed confidentiality from Transcriptionist

Project- First Episode Psychosis: The experience of Parent Caregivers

Jane Hamilton Wilson

CONFIDENTIALITY STATEMENT

I certify that I will keep confidential and secure and will not copy, give or otherwise disclose to any other party who has not signed a copy of this confidentiality agreement, any information which I learn in the course of my transcription duties on this project. I understand that all information is to be kept confidential. This includes all audio files as well as written or electronic materials.

Date: June 20. 2010

Signature:

Printed Name: Charmain Kirkland

Appendix I: Information Letter and Informed Consent

St. Joseph's
Healthcare Hamilton

St. Joseph's Healthcare Hamilton
FEB 0 1 2010
Research Ethics Board

Project Title: *First Episode Psychosis: The experience of parent caregivers*

Local Investigator:

Dr. Suzanne Archie, MD., Cleghorn Program, 703-25 Charlton St., Hamilton.
Phone : 905- 540-6586, email address archies@mcmaster.ca

Principal Co-Investigators:

Sherrill Conroy, RN, D. Phil, Assistant Professor, Faculty of Nursing, University of Alberta, phone: (780) 492-904, email address: sherrill.conroy@ualberta.ca s

Wendy Austin RN, PhD, Professor, Faculty of Nursing, University of Alberta, phone: (780) 492-5250 email address: wendy.austin@ualberta.ca

PhD Student Co-Investigator:

Jane Hamilton Wilson, RN, PhD candidate, Faculty of Nursing, University of Alberta, phone: 519-748-5220 ext 3901,email address: jeh3@ualberta.ca

Study Purpose: This student research study will examine the lived experience of parents of youth or young adults with emergent psychotic disorder. The overall goal of this research is to increase understanding of the impact of this experience upon mothers and fathers who are engaged as primary caregivers during the initial phase of assessment, diagnosis and treatment for first episode psychosis. Parents' narrative accounts of their experiences with their ill son or daughter will be elicited, transcribed and interpreted.

What will happen? We will talk with you by yourself the first time in person. If you agree, we will also talk with you one more time at a later date. These talks will be recorded. We expect that it will take about 60-90 minutes for us to talk together. The follow up talk will not be more than 45-60 minutes long. We will invite you to read a short summary of our findings.

What are the benefits of the study? There is no individual benefit to you for participating. Your story will help us to learn about parenting a child with first episode psychosis, and to understand what helps and does not help. What you tell us may be helpful to people who plan programs to support other mothers and fathers.

Are there any risks to me? The only risk is that you may possibly feel uneasy or upset about what you tell us. If you feel upset during the interview, we will talk with you and help you decide how to deal with your feelings. You can decide to stop at any time. We will also help you to find support within the Cleghorn Program.

Will my privacy be protected? We will keep your name and what you say private. We will use a code number on study materials. Only the research team and the person who types out the recorded interviews will know what you said. This person will sign an oath to keep what you say private. You will not be named in any reports or talks about this study. Your actual words may be used, but not your name or any information which could identify you. Any quotes used will be free from identifying information. The researchers will store the study data in a locked file drawer in a secured office accessible only by pass key at Conestoga College, Kitchener. The study data will be kept for at least ten years after the study is finished. The study data may be used again in another study with approval from an ethics board. All information will be held private except when professional codes of ethics or the law requires reporting.

It's your choice It is your choice to be part of this study. You may choose to talk with us only one time. You may choose not to answer some questions. You may ask questions at any time. If there are things that are upsetting you, we will find someone for you to talk to.

Can participation end early? Choosing not to participate or deciding to withdraw from participation will not affect current or future care within the Cleghorn Program.You may withdraw from the study at any time. You may turn off the recorder at any time . You will be able to withdraw right up until your story is transcribed and analysis has been initiated by members of the research team. After this analysis has begun your individual story cannot be withdrawn.

Reimbursement of expenses you will be reimbursed $10 for your parking fees

If you have any questions You can call Jane Hamilton Wilson 519-748-5220 ext. 3901or email me at jeh3@ualberta.ca

Additional contacts:

Dr. Suzanne Archie, MD, Cleghorn Program, 703-25 Charlton Street, Hamilton, Ontario. Phone : 905- 540-6586, Email: archies@mcmaster.ca

Dr. Sherrill Conroy, RN, DPhil, Associate Professor, my research co-supervisor, Faculty of Nursing, University Of Alberta, at 780- 492-9043. Email: sherrill.conroy@ualberta.ca

Dr. Wendy Austin RN, PhD, Professor, my research co-supervisor, Faculty of Nursing, University of Alberta, phone: (780) 492-5250. Email address: wendy.austin@ualberta.ca

If you have any concerns about this research or your rights as a participant please contact:

The Office of the Chair, St Joseph's Healthcare REB, at 905-522-1155 x 33573

Study findings If you would like a summary of the final results of this study, please call Jane Hamilton Wilson at 519-748-5220 x 3901. Please leave your name, and mailing address including a postal code.

Part 2 (to be completed by the research participant)

Do you understand that you have been asked to be in a research study?	**Yes**	**No**
Have you read and received a copy of the attached Information sheet?	**Yes**	**No**
Do you understand the risks and benefits involved in taking part in this research study?	**Yes**	**No**
Have you had an opportunity to ask questions and discuss this study?	**Yes**	**No**
Do you understand that you can withdraw at any time from the study without having to give a reason? Withdrawing from the study will not affect your care in hospital or in the community.	**Yes**	**No**
Has the issue of confidentiality been explained to you?	**Yes**	**No**
Do you understand who will have access to your records?	**Yes**	**No**
Do you understand that the interview will be audio-taped?	**Yes**	**No**

Do you authorize that your records be utilized for another research project following the submission of a new research proposal to an ethic review board and received approval?

Yes **No**

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name Signature Date

Person obtaining consent:

I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name, Role in Study Signature Date

This study has been reviewed by the SJHH Research Ethics Board (REB). The REB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call The Office of the Chair, SJHH REB at 905.522.1155 x 33537.

***The information sheet must be attached to this consent form and a copy given to participant..**

Are there any risks to me? The only risk is that you may possibly feel uneasy or upset about what you tell us. If you feel upset during the interview, we will talk with you and help you decide how to deal with your feelings. You can decide to stop at any time. We will also help you to find support within the Cleghorn Program.

Will my privacy be protected? We will keep your name and what you say private. We will use a code number on study materials. Only the research team and the person who types out the recorded interviews will know what you said. This person will sign an oath to keep what you say private. You will not be named in any reports or talks about this study. Your actual words may be used, but not your name or any information which could identify you. Any quotes used will be free from identifying information. The researchers will store the study data in a locked file drawer in a secured office accessible only by pass key at Conestoga College, Kitchener. The study data will be kept for at least ten years after the study is finished. The study data may be used again in another study with approval from an ethics board. All information will be held private except when professional codes of ethics or the law requires reporting.

It's your choice It is your choice to be part of this study. You may choose to talk with us only one time. You may choose not to answer some questions. You may ask questions at any time. If there are things that are upsetting you, we will find someone for you to talk to.

Can participation end early? Choosing not to participate or deciding to withdraw from participation will not affect current or future care within the Cleghorn Program. You may withdraw from the study at any time. You may turn off the recorder at any time . You will be able to withdraw right up until your story is transcribed and analysis has been initiated by members of the research team. After this analysis has begun your individual story cannot be withdrawn.

Reimbursement of expenses you will be reimbursed $10 for your parking fees

If you have any questions You can call Jane Hamilton Wilson 519-748-5220 ext. 3901or email me at jeh3@ualberta.ca

Additional contacts:

Dr. Suzanne Archie, MD, Cleghorn Program, 703-25 Charlton Street, Hamilton, Ontario. Phone : 905- 540-6586, Email: archies@mcmaster.ca

Dr. Sherrill Conroy, RN, DPhil, Associate Professor, my research co-supervisor, Faculty of Nursing, University Of Alberta, at 780- 492-9043. Email: sherrill.conroy@ualberta.ca

Dr. Wendy Austin RN, PhD, Professor, my research co-supervisor, Faculty of Nursing, University of Alberta, phone: (780) 492-5250. Email address: wendy.austin@ualberta.ca

If you have any concerns about this research or your rights as a participant please contact:

The Office of the Chair, St Joseph's Healthcare REB, at 905-522-1155 x 33573

Study findings If you would like a summary of the final results of this study, please call Jane Hamilton Wilson at 519-748-5220 x 3901. Please leave your name, and mailing address including a postal code.

Part 2 (to be completed by the research participant)

Do you understand that you have been asked to be in a research study?	**Yes**	**No**
Have you read and received a copy of the attached Information sheet?	**Yes**	**No**
Do you understand the risks and benefits involved in taking part in this research study?	**Yes**	**No**
Have you had an opportunity to ask questions and discuss this study?	**Yes**	**No**
Do you understand that you can withdraw at any time from the study without having to give a reason? Withdrawing from the study will not affect your care in hospital or in the community.	**Yes**	**No**
Has the issue of confidentiality been explained to you?	**Yes**	**No**
Do you understand who will have access to your records?	**Yes**	**No**
Do you understand that the interview will be audio-taped?	**Yes**	**No**

Do you authorize that your records be utilized for another research project following the submission of a new research proposal to an ethic review board and received approval? **Yes** **No**

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name Signature Date

Person obtaining consent:

I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name, Role in Study Signature Date

This study has been reviewed by the SJHH Research Ethics Board (REB). The REB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call The Office of the Chair, SJHH REB at 905.522.1155 x 33537.

***The information sheet must be attached to this consent form and a copy given to participant..**

Appendix J–One P and Ten R's Munhall's Criteria

Criteria Name	Criteria Description
Phenomenological Nod	Symbolically nodding in agreement when reading or listening when reading or listening to study's findings
Resonancy	The interpretation of the meaning of the experience is familiar, sounds correct, resonates with past experiences
Reasonableness	All activities of the study, including the interpretation of meaning of the experience sound reasonable; the researchers presented carefully reasoned rationale of all aspects of the study
Representativeness	The findings represent the many dimensions of the lived experience; this is evident because of the multiple data sources examined
Recognizability	The reader becomes more aware of an experience by recognizing some aspects of that experience, leading to raised consciousness
Raised consciousness	The reader focuses on and gains understanding of an experience, about a new insight not thought before
Readability	Writing should be concrete readable, interesting and understandable
Relevance	Research findings should bring us close to our humanness, increase our consciousness, enable understanding, give us possible interpretations, offer us possible meaning and guide us in our lives personally
Revelations	As the reader gains a deeper understanding, behind or underneath

	what is revealed to us, we have considered what is being concealed or what wishes to be concealed
Responsibility	Ethical considerations are evident, including process consent, sensitivity to content of conversations, and authentic representation of meanings
Richness	Full bodied, multifaceted, multilayered, thoughtful, sensitive, impassioned description of a human experience
Responsiveness	People are moved to rethink preconceptions or to act in some way in response to the study
Adapted from Munhall, as cited in Mackey, M, (2007), Evaluation of qualitative research, P. Munhall, (ed.) *Nursing research: a qualitative perspective.* p. 562	

Appendix K Sample Field Notes

Participant Code: __________

Date of interview: __________________ Date of field notes: ___________________

Participant: *(physical appearance, demeanor, communication style)*

Situated Context: *(physical setting, environment of interview, unanticipated event, concurrent activities/interruptions, presence of others)*

Temporal context: *(time and duration of interview)*

Non-verbal behaviors/communication:

Affective tone of the interview: *(emotional content, mood, researcher's role)*

Dynamics: *(direction of the interview, domination of interaction, interruptions, silences, mutuality of exchange, rhythm, convergence)*

Engagement: *(perceived/experience of rapport, openness of participant, required openness of researcher, perceived/noted areas of friction)*

Interactional goals: *(participant's explicit motive for participating, potential implicit motives, success in eliciting narratives, stumbling blocks, potential modifications)*

Researcher's emotional reactions:

Overall evaluation of the interview: *(general impressions, additional concerns, perceived effectiveness)*

Appendix L – Sample Interpretive Worksheet

Participant Code: __________

Aspect I **Attending to footprints** **Attending to Concurrent Interpretation**	**Aspect 2** **In-depth** **interpretation**	**Aspect 3** **2nd Reader Interpretation**	**Aspect 4** **Paradigm Shift Identification**	**Aspect 5** **Exemplar Identification**	**Aspect 6** **Identification of Principles**

APPENDIX M: Sample Summative Worksheet In-depth Interpretation

Participant Code__________

Conversation Session #	**Interpretation**

APPENDIX N – List of Available Supports and Resources

If you are experiencing any type of distress

***call your family doctor.**

If you do not have a family doctor,

You can also call:

➢ Cleghorn Family Educator	905-540-6586
➢ COAST Services Hamilton Crisis Line 24 hours -	905-972-8338

If there is an immediate crisis or risk:

- ✓ Go to the nearest emergency department at any hospital
- ✓ Call Hamilton City Police dial **911**

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