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# UNIVERSITY OF CALGARY

Mothers' Experience Seeking Help with Children Suffering Depression

by

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### A THESIS

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### Abstract

This study used a narrative inquiry design to explore knowledge woven through five mothers' experience seeking help with children suffering depression. Emerging threads in mothers' stories included: defining a problem, negotiating the system, stigma, and uncertainty. Through collaborative analysis intertwined threads evolved: discerning a pattern, nominating true supports, significance, and understanding. Links to dominant narratives were discussed. The implications of a narrative paradigm for research and practice were considered.

# Dedications

For
Rosemary Mackie, my mother
and
Esther Veronica Dunbar, my mother's mother

# Acknowledgements

The work of the researcher and participants toward crafting this fabric of knowledge is visible in the text of this thesis. Others have made significant contributions that I would like to acknowledge here.

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Thank you all.

Sincerely,

Fiona Odorico

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# Chapter One

### Introduction

Individually and collectively, humans make sense of experience through the use of narrative (Harrell, 1983; Boykin & Schoenhofer, 1991; Connelly & Clandinin, 1990; Clandinin & Connelly, 1994; Sandelowski, 1991, 1994). A narrative or story, however, is different from what actually happened or was experienced (Sandelowski, 1994). Hearing the story of a person or group does not give special access to the experience (Atkinson, 1997). The continued living of a life and each act of telling results in retellings and reinterpretations (Sandelowski, 1991; White & Epston, 1990). Persons story their lives according to the narrative models or templates available to them in their culture. Researchers for example, speak in the third person and structure research reports in standardized formats that obscure the narrativity of science (Sandelowski, 1991).

The story of depression has a long history in Western culture (Jackson, 1986). In early Greek times depression was thought to afflict adult and adolescent males. It was thought to be associated with intelligence and thoughtfulness. It was believed that women and children were not affected. Efforts to understand and treat depression focused on medical treatment, through the balancing of the different humours. The essentially medical structure of this story remained unchanged (although the specific content varied) until the Victorian era. Changing family roles, the evolution of childhood and the emergence of psychoanalytic thought altered the framework within which the stories of depression were told.

Today depression is identified as a major public health concern (Modrein-McCarthy & Dalton, 1996). It is the most commonly diagnosed mental health problem (Greenberg, Stiglin, Finklestein, & Berndt, 1993; Horwath, Johnson, Klerman, & Weisman, 1994; Judd, 1995; Judd, Paulus, Wells, & Rappaport, 1996; Ormel, VanKorff, Ostun, Pini, Korten & Oldenhinkel, 1994). Whether one interprets depression as a mental illness, (American Psychiatric Association, 1994) or as the distress resulting from experiences of loss or oppression (Hopton, 1996; Pugliesi, 1992; Steen, 1991), it is a form of suffering that affects a significant proportion of the population.

Until quite recently children were not present in the story of depression, nor was depression recognized to exist in the stories of children. The American Psychiatric Association first entered the framework for the story of children and depression in the Diagnostic and Statistical Manual (DSM) in 1968 (Parry-Jones, 1995). There have been three retellings of this story since, the most recent being the DSM-IV (American Psychiatric Association, 1994). Most recent tellings of the stories of children and depression speak of genetics, chronic illness, family relationships and interaction patterns, and social support.

Stories that speak of family, on closer reading, are most often speaking of mother and child. Mothers are described as critical (Chilcoat & Breslau, 1997; Pike & Plomin, 1996), too emotional (Dadds, Sanders, Morrison, & Rebgetz, 1992), unemotional (Oliver & Paull, 1995), unavailable (Rodriguez-Vega, Canas, Bayon, & Franco, 1996), too available (Gjerde, Block, & Block, 1991) and at best as lacking social support (Goodyer, Herbert, Tamplin, Secher, & Pearson, 1997). The dominant stories in the literature touch lightly on the connections between the mother-child dyad, other family, friends, community and health care system. Most often mothers are viewed as one of a number of distinct variables impacting on children's well being. Statistical analyses may provide statistically significant interactions but are unable to explore meaningful experiential connections.

This study aims to create a space in which the stories of mothers' experiences seeking help with children suffering depression may be heard and developed. The purpose of this study is to understand the experience of seeking help and how this experience is endowed with meaning.

# Purpose of Study

The review of the literature that follows may be seen as an analysis of a multilayered fabric of knowledge. One layer is constructed of narrative threads related to child and adolescent depression. Within this layer threads examining the role of family may be seen as arising from threads within an underlying fabric of knowledges about mothering.

Threads from this underlying layer may be seen to speak of a simultaneous burdening and isolating of women who mother children who may experience depression.

These themes of burden and isolation may be seen to join with threads describing individual and family experience with depression and mental illness.

There are many openings for study in this developing multi-layered fabric of knowledge. Thick strands describe mothers' influence on their children's mental health and the benefits of social support. Fewer, thinner threads describe the experience of isolation and the social context within which it occurs. I believe that connecting the layers of child depression, mothering and help seeking may contribute to a richer, stronger fabric of knowledge. The purpose of this study is to develop understanding of mothers' experience seeking help with children suffering depression. Mothers may experience help-seeking as a process of connection, misconnection, and/or disconnection (Wuest, 1995, 1997). This experience may also be one of powerlessness and/or powerfulness (Rutman, 1996). Conversations with mothers may construct understandings unavailable through review of the literature or clinical experience.

Part of the reason for this inquiry is to foster nurses' understanding of mothers' experience of seeking help with a child suffering depression. My experience as a nurse and a mother, and my interpretation of the literature led me into this study with questions about the sources of strength, stress, and support in this experience.

# Significance of the Study

A research based understanding of mothers' experience seeking help with a child suffering depression may serve to guide or support the caring practice of nurses working with families and the education of future nurses. Collaborative research that includes the voice of mothers can change nursing practice through the production of knowledge that offers new paradigms or discourses (Keddy, 1996; Rose, 1996). These new paradigms or discourses may in turn broaden the range of questions that are asked and knowledges that may be constructed to develop nursing practice.

This study may introduce a small thread into the fabric of nursing knowledge through the sharing of findings in publications and presentations. At a minimum it represents a beginning reweaving of the fabric of knowledge supporting my practice. The

process of coming to the question involved examining the assumptions underpinning this knowledge such that I no longer feel comfortable assuming that I know what is best for the families and children I work with in my practice. I anticipate that consciously participating in collaborative data generation and analysis will contribute to the development of a more natural collaborative and reflective approach in my practice.

# Research Question

The research question guiding this study comes out of my experience as much as it comes from my review of the literature. I have extended the metaphor of weaving to the relationship between these two: the warp or lengthwise threads of a review of literature, and the weft or crossing threads of experience. In doing so, I am acknowledging that the experiences I relate are chosen by me to craft a particular understanding.

I come to this question as a woman who experienced mothering first, as most of us do, through being mothered. I was mothered by a woman who was mothered by a woman who was labelled as depressed. In my teens my mother also was diagnosed as depressed and me response at that time would now likely be labelled depression.

My question is not about the label or description of depression. My experience has instructed me that beneath that label lies suffering, for the identified individual as well as those who care for them. My question is more about the alleviation of suffering. This general question led me into nursing, and not surprisingly, mental health. Guided by a belief that suffering could be prevented I shifted from working with adults to children and then developed an interest in working with families.

My initial work with families was guided by a child-centered experience of families. This was tested when I became a mother myself and experienced the dilemma of empathizing with the parents as well as the children who sat in my office. I also developed a beginning appreciation of the social context of my own mother's suffering.

The experience of attempting to balance the roles of graduate student and mother (among others seemingly pushed to the edge of memory for now) while living apart from my home community collapsed into a period of extended questioning and a reacquaintance

with the phenomena of depression. Out of this self questioning have come simultaneously a new appreciation for the importance of social support and some of the challenges inherent in seeking help. I have also come to an uncomfortable recognition of the subtle mother blaming that has underpinned my own practice. So although I may extend hopes that this study may help to change nursing practice, engaging in this study is a deliberate first step in changing my own practice.

This qualitative study, using narrative inquiry, explores the experience of mothers seeking help with children suffering depression. The specific question is: What knowledge is embedded within mothers' experience of seeking help with a child suffering depression that may influence nursing practice? As this inquiry evolves in the context of conversational interviews other questions emerge in the course of conversation. These questions attend to the participants' story as well as the researcher's intent to develop understanding of mothers' help seeking experience with a child suffering depression.

### Chapter Two

### Literature Review

Research literature may be seen as the fabric within which health professionals construct an understanding of a phenomena of interest, and therefore the way in which persons experiencing this phenomena are understood and approached. Trends in the literature may be seen as threads or yarns that interlace and weave into a fabric of knowledge. The assumptions and beliefs expressed above may be seen as a frame or loom within which the understanding guiding this proposal is crafted. This literature review will trace the warp and weft of this fabric, the dominant and emerging narratives regarding child and adolescent depression and its contexts.

In weaving, the warp is made up of the length wise threads in the loom. In this review literature exploring understanding through measurement, quantitative studies, will be considered to function as the warp. Threads woven across the warp to make fabric are called the weft. Literature seeking to understand the meanings of phenomena may be seen as the weft. Meanings may be explored through reviews of research, clinical literature, and qualitative studies. With effort, experience, and skill, one may craft a fabric without a loom or frame. A serviceable and strong fabric, however, requires many strands of both warp and weft.

Threads from either or both the warp and weft may organize themselves into visible patterns or theories, some remaining distinct from each other, others dovetailing or overlapping. Again the particular frames or paradigms available will proscribe the length, breadth and complexity of the fabric that may be crafted.

Modernist, structuralist, and science-centered frames exclude the knowledges that may be crafted at the borders and add to the utility of the fabric of knowledge (Miller, 1997). Research conducted within these frames examine the biology, psychology, and family environments of children from an objectivist perspective. These frames aim to construct unified descriptions or explanations of child and adolescent depression that will develop the knowledge on which professional interventions are based.

Postmodernist, poststructural, and critical feminist frames introduce threads

from the borders that may enrich the patterns at the centre. These frames assume that there will be many truths, and that attention to context, particularly in relation to gender and power relations within a society, will make space for these truths to be told. The proposed study aims to use these broader frames so that multiple truths from the centre and the borders may be considered in developing understanding. Clandinin and Connelly (1994) assert that a narrative approach is consistent with these aims and frames.

### Depression in Children and Adolescents

The narrative threads brought forward from Hippocratic times describe depression as an individual, largely biological phenomena (Jackson, 1986). Children were not considered in these narratives until the 19th century (Parry-Jones, 1995). Childhood depression remained controversial into the 1960s. Some authors considered children not sufficiently mature to experience depression (Mahler, 1961). However, other authors documented the existence of depressive symptoms among children and adolescents (Sandler & Joffe, 1965).

Most research narratives speak of adolescent depression (Brage, Campbell-Grossman, & Dunkel, 1995; Williamson, Ryan, Birmaher, Dahl, Kaufman, Rao & Puig-Antich, 1995; Adams & Adams, 1996; Sheeber, Hops, Alpert, Davis, & Andrews, 1997; Patten, Gillin, Farkas, Gilpin, Barry, & Pierce, 1997; Garrison, Waller, Cuffe, McKeown, Addy, & Jackson, 1997). The importance and urgency of gaining knowledge in this area is highlighted in narratives linking depression to suicide (Hollis, 1995; Fennig & Carlson, 1995; Adams & Adams, 1996; Modrein-McCarthy & Dalton, 1996). Modrein-McCarthy and Dalton (1996) suggest that younger children may remain unmentioned in these narratives due to assumptions guiding the recording of childhood "accidents" and deaths.

Narratives regarding the prevalence of depression in children and the presenting symptoms vary in the truths they present. Depending which "symptoms" are selected depression may be seen to be more (Modrcin-McCarthy & Dalton, 1996; Garrison et al., 1997) or less (Fleming, Offord, & Boyle, 1989; Fennig & Carlson, 1995) common. Again depending on the construct of depression that is used gender differences may (Hagerty,

1995) or may not (Modrcin-McCarthy & Dalton, 1996; Fasser & Dumas, 1998) be seen to exist in prevalence rates.

Held together these threads may be taken as initial attempts to understand changes in the mental health of children and adolescents. More children and adolescents may be becoming depressed. Awareness of the emotional "realities" of childhood may be broadening. Values may be shifting about what constitutes mental health in children, including who assumes responsibility for the mental health of children and youth.

Studies examining the individual experience or meaning of depression are, so far, limited to explorations of adult's (Karp, 1994), women's (Schreiber, 1996a, 1996b; Steen, 1996), and mother's (Beck, 1996; Small, Brown, Lumley & Astley, 1996) experiences. Isolation and disconnection are common themes emerging in these studies of individual's experiences of depression.

# Families, Children and Depression

Some threads relate depression in children to depression in other family members and suggest genetic (Kovacs, Devlin, Pollock, Richards, & Mukerji, 1997; Harrington, Fudge, Rutter, 1990) or learning (Stark, Humphrey, Laurent, Livingston, & Christopher, 1993) links. Other threads explore the relationship between child and adolescent depression and family structure (Patten, Gillin, Farkas, Gilpin, Berry, & Pierce, 1997), family cohesion or support (Kashani, Allan, Dahlheimer, Rezvani, & Reid, 1995; Sheeber, Hops, Alpert, Davis, & Andrews, 1997), and family interaction patterns (Chiarello & Orvaschel, 1995; Dadds et al., 1992). These threads lead to recommendations for treatment with medications, cognitive-behavioural therapy and family therapy.

One very thin thread indeed (McLeod & Shanahan, 1996) links higher rates of depression in children with living in poverty, a state that may affect dimensions of family function as well. Another thin thread (Verhulst, Frank, & van der Ende, 1997) carries the cautionary note to clinicians and researchers that families in their samples are those who face many challenges with limited resources.

A small but growing thread of narrative explores families' experience with

mental illness in a family member (Badger, 1996; Jeon, 1998; Rose, 1996, 1998a, 1998b). These narratives focus more on families of adults, and family members with schizophrenia. This focus, however, is not exclusive and parents of adolescents with depression have been included among the participants in these studies. This thread includes stories of burden, isolation, stigma, struggles to make sense of their loved one's behaviour, and to maintain relationships. Could these narratives suggest future directions for research with child and adolescent depression? Or are different assumptions about the role of families in the lives of children and adults framing the construction of knowledge?

### Mothers and Help Seeking

On closer reading research and clinical narratives referring to "family" speak of mother-child dyads. The minor role assigned to fathers in these narratives is surely an area worthy of study. However in this study my purpose is to describe mothers' experience within a fabric already thick with threads that describe or proscribe their role in child and adolescent depression. I propose to do this by entering into conversations with mothers about their experience of seeking help and how they understand this experience.

Mothering in this culture, in this century has been idealized as a woman's primary, even sole, mission during her children's formative years (Glenn, 1994). The idea of maternal responsibility may be seen as collusion with a societal denial of mother's powerlessness (Weingarten, 1994). The process of medicalization shifts the focus of health responsibility from a sociopolitical to an individual context (Wuest, 1995). Women's experiences in families reproduce their assumption of caring responsibility for family members. In response to competing demands for caring, societal expectations, and policy decisions affecting supports available, women experience dissonance, fraying connections, and values conflicts with health professionals and those in their care (Wuest, 1995; Rutman, 1996). Powerfulness is experienced by women caregivers through effecting positive change, having and sharing expertise, and recognizing and attending to one's own needs.

Pridham (1997) describes help-seeking as caregiving in a social context. Could the literature on help-seeking provide clues to this social context? Some of these narratives

suggest that help seeking may be influenced by the perceived cause of the behaviour that help is being sought for (Fosu, 1995; Pugliesi, 1992; Salguero & McCusker, 1996). How might these threads interweave with other threads describing struggles to make sense of a loved one's changing behaviour (Badger, 1996; Jeon, 1998; Rose, 1996, 1998a, 1998b)? Another series of threads relates parents' (mothers) help seeking to their perceived sense of competence (Verhulst & van der Ende 1997; McMiller & Weisz, 1996; Telleen, 1990). How might this be affected by stigma or societal expectations of mothers? Still another group of studies speaks of help seeking being influenced by the quality of the parent professional relationship (Garrison, Bailey, Garb, Ecker, Spencer, & Sigelman, 1992; Wildman, Kinsman, Logue, Dickey, & Smucker, 1997; Wissow, Roter, & Wilson, 1994). How might these understandings interweave with McGregor's (1994) suggestion that professionals may neglect or pathologize parent grief related to a child's mental health problem?

What sense can be made of all this? Mohr and Fantuzzo (1998) recommend that future research related to children's mental health be collaborative and cognizant of context. Parents can provide information rich with potential for systems change that is unavailable to professionals (Tarico, Low, Trupin, & Forsyth-Stephens, 1989). Hauenstein (1992) asserts that the "maternal deficit model" has misdirected research away from situational factors influencing parent child relationships. Women's concerns must be documented to figure in policy making. Pridham (1997) recommends a narrative approach to learn about conditions associated with mothers' help seeking as well as to obtain a full sense of the meaning and expectations of seeking help.

# Chapter Three Design and Methods

### **Experience and Assumptions**

Clandinin and Connelly (1994) recommend that the researcher using personal experience methods consider the experience that has brought her to this study and the role that she will play in the stories of participants. Thorne and Varcoe (1998) caution against simply labeling or describing categories of experience. Explication of the researcher's assumptions, values and biases may facilitate a more useful analysis of the researcher's frame of reference.

I come to this study (as I came to mental health nursing) as the daughter and granddaughter of women identified as suffering depression. My own responses, as an adolescent, to my mother's depression and the context that it occurred within, may have earned me a diagnosis of depression had my mother's help seeking experience led to different connections. Coming from this experience I look at the literature on family interaction patterns and relationships and say "So what? How does this knowledge help? How does this knowledge make a difference in the lives of women and children?"

I also come to this study as a mother. Mother is not an absolute and universal category. I am a woman who became a mother at the relatively late age of 37. I became a mother after being a mental health professional for 12 years. For me the years preceding becoming a mother were years of viewing families from a child centered perspective.

Negotiating the conflicting roles of mother, mental health professional and graduate student I have come to reflect with some discomfort on the subtle mother blaming that was a part of my practice, how much courage it takes to ask for help, and the complexity and importance of social support.

It is my belief that mothers' experience seeking help with children suffering depression is a topic worthy of study. I believe that knowledge and meaning are found and created in these experiences. Stories of professional helpers' experience are told in theory, clinical literature and research reports. Telling the stories of mothers' experience broadens and deepens our shared knowledge base. I do not seek to provide THE map of this

experience, rather I aim to open up possibilities for further understanding and sensitivity to the unique experiences of families.

In my experiences I have come to believe that depression is a broad and complex phenomena that occurs in a social context. Understandings of depression that focus solely on its biological aspects isolate and disempower families experiencing the presence of depression. Depression is a word with many connotations in its multiple common and even clinical usages. I am choosing to view this ambiguity as an opportunity to privilege mothers' expressions of concern and broaden the range of stories that may be shared.

I believe that families are the experts of their own experience. It is our responsibility, as nurses, to engage in attempts to understand the fullest possible context of families' health experience. This improved understanding may improve the practice of myself, other nurses, and possibly the quality of service provided to families undergoing similar experiences.

### Narrative Inquiry

In crafting the design for this study threads were drawn from the fabric of knowledge relating to narrative research. Polkinghorne (1988) reviewed the treatment of narrative by the disciplines of history, literary theory, psychology and in the work of Heidigger with the purpose of assembling a narrative theory for the practice of the human disciplines. Connelly & Clandinin (1990) and Clandinin & Connelly (1994) consider narrative inquiry as a method of researching personal experience that bridges both raw sensory experience and cultural forms that may obscure the particular. These writers outlined criteria, methods and writing forms applicable to the use of narrative inquiry in educational research. Sandelowski (1991) offered examples of narratives, considered the issue of truth in narrative, and contrasted narrative analyses with other types of qualitative analyses pertinent to nursing research.

Narrative researchers describe lives, collect and tell stories of them, and write narratives of experience (Connelly & Clandinin, 1990). Narrative paradigms may be seen as providing frameworks for understanding the human being as the subject of nursing inquiry,

conceptualizing the interview, analyzing and interpreting the interview data (Sandelowski, 1991).

Narrative research may be descriptive and/or explanatory (Polkinghorne, 1988). This study is descriptive in nature. Descriptive narrative research produces a document describing the narratives within or below awareness that make up the interpretive schemes used to establish the significance of past events (Polkinghorne, 1988). This study, then, will produce a document describing the narratives that make up the interpretive schemes used to establish the significance of seeking help with a child suffering depression. Descriptive research may also describe the function that particular episodes serve in individual's emplotments of their lives, the relationship between individual stories and the culturally available stock of stories, and the conditions under which a storyline or signification of events prevails, over coheres with, or conflicts with other storylines (Polkinghorne, 1988; Sandelowski, 1991). By contrast explanatory narrative research aims to explain why an event has happened through the construction of a narrative that orders events so that the "cause" of the happening under investigation becomes apparent (Polkinghorne, 1988).

Different methods of data collection are possible as the researcher and participants work together in a collaborative relationship. These may include field notes, journal records, interviews, conversations, letter writing, and images. In this study, conversation will be the primary means of data (or story) collection. Conversation entails listening and responding to participants' stories, between pairs or among groups of individuals, in a manner less constraining of participants' responses than a structured research interview (Clandinin & Connelly, 1994). Interpretation is inevitable in narrative inquiry, it is embedded even in the data collection process (Connelly & Clandinin, 1990).

The gathering of narrative statements is followed by an analysis that includes the context of the research situation as well as participants' responses (Polkinghorne, 1988). In this study one on one conversations were tape recorded and transcribed to facilitate a collaborative crafting of narratives. Group conversations were to focus on crafting a document or documents recording mothers' experience seeking help and their reflections on this experience. The group included the researcher and participants in one on one

conversation who elected to also collaborate in data analysis. The research context of group conversations was attended to through journalling by the researcher.

"If we wish to hear respondents' stories, then we must invite them into our work as collaborators, sharing control with them, so that together we try to understand what their stories are about." (Mishler, 1986 cited in Polkinghorne, p.164). A collaborative approach is consistent with postmodern, post-structural, and feminist frameworks. In collaborative work, the shifting interests and intentions of more than one participant need to be kept in rhythmic balance for the study to proceed. However given an assumption of multiple coexisting realities and the possibility of understandings not accessible from the perspective of all participants (Thorne & Varcoe, 1998) the researcher is ultimately responsible for the final text, keeping interpretations close to the data.

The researcher seeks narrative probability and fidelity, and aesthetic finality (Sandelowski, 1991). That is, does the story make sense? Is it consistent with past experience or other stories? Is there satisfactory closure and representational appeal? What preoccupies the researcher is how experience is endowed with meaning through narrative structures of voice, place, temporality, and multiple I's. This final text examines patterns, narrative threads, tensions, and themes within and/or across individuals' participants experience (Clandinin & Connelly, 1994).

### Selection of Participants

This narrative study sought participants who were able to speak of their experience as a mother seeking help with a child suffering depression. This strategy, ensuring that all participants represent people who have experienced the phenomena being studied, has been called purposive, criterion sampling (Creswell, 1998). Colleagues and participants were also asked if they knew of mothers who would wish to contribute to this research by sharing their experience. This strategy has been called snowball or chain sampling and can facilitate generating information rich data (Creswell, 1998). Selected participants were:

mothers who have been concerned that their child may be depressed,

able to converse in English,
willing to speak about their experience of seeking help,
given the opportunity to join in a group collaborative analysis.

The terms mother and child here signify relationships. Mothers may be biological, adoptive or foster mothers. Child(ren) refers to minors, ranging in age from early childhood to late adolescence, who are cared for by these women.

The literature on child and adolescent depression presents a range of opinions as to the prevalence and presenting symptoms of depression amongst children and adolescents. In consideration of this and the fact that this study focused on the experience of seeking help, the mother's definition of depression was privileged. Their children need not have received a medical diagnosis of depression.

This study aims to broaden the range of stories that may be heard and richly describe mothers' experience of seeking help with children suffering depression. Selected participants need not have sought help from formal systems. The experience of seeking help need not be concurrent with participation in the study.

Some participants were recruited through clinician referral and/or posters placed in the waiting area of a child and adolescent treatment centre in western Canada. An abstract of this proposal was forwarded and approved by Children's Mental Health Research Committee members. Once ethical approval had been received from the Research and Scholarly Development Committee, Faculty of Nursing, University of Calgary the full proposal was forwarded. No additional ethical or scientific review will be conducted by the treatment facility's research committee.

# Number of Participants

In the study of experience it is the researcher's intentionality that defines the starting and stopping points (Clandinin & Connelly, 1994). The purpose of this study is to develop understanding of mothers' experience seeking help with children suffering depression. It was anticipated that the study would start with one or two participants and grow as recruitment of participants was deemed necessary to further explore the help-

seeking experience. Mothers who have participated in one on one conversations were invited to participate in group conversations. Through collaborative conversations with participants, journalling, and consultation with thesis committee members the researcher decided when a sufficiently rich description and understanding of this experience had been achieved.

# Data Generation

Unstructured interviews, conversations, story telling, photographs, journalling or letter writing have all been described as data collection tools in narrative inquiry (Connelly & Clandinin, 1990). Material written throughout the course of the inquiry, even material written for other purposes, such as a presentation to parents regarding childhood depression, have become part of the final document. Data was collected until the final document, the research text, was completed. This study has generated data through one to one conversation, group conversation, and journalling.

Demographic data (marital, income, educational, and occupational status; age; number and ages of children; racial and/or ethnic background) were collected from each participant to provide a context within which to understand their experience. The primary means of data generation with participants was one to one conversation. Conversations were initiated with a question such as "What has it been like to seek help with your child?".

Each conversation was audiotaped and transcribed. After the first meeting the researcher drafted a narrative of the participant's experience which was brought, with transcript, to the second meeting for further interpretation. Most meetings would take approximately one hour. Additional meetings were scheduled as needed to facilitate completion of the narrative.

Group conversations provided opportunities for deeper exploration and further negotiation of meaning (Cresswell, 1998). After participation in one to one conversations was completed, participants were invited to share their stories with each other as part of a collaborative analysis of these narratives of experience. All participants elected to share their written narrative before the first meeting and to share their stories verbally. These conversations were guided by the research question with the aim of accessing participants'

expert knowledge of this experience. The aim was to create a document or documents recording and reflecting on the experience of seeking help with a child suffering with depression. Additional meetings were scheduled as mutually agreeable to facilitate a reasonable understanding. These meetings took approximately two hours each.

Journalling by the researcher served as a record of the research process and context of these group conversations. This also served as a resource for reflection and further discussion during group meetings. Participants were offered the option of videotaping these group conversations as an additional record and resource for interpretation. This option was not exercised due to unforeseen technical difficulties. The researcher maintained a journal for the duration of the study as a record of and reflection on the research process.

### Data Analysis

Data analysis began immediately during the first individual meetings, as the researcher and participants entered into conversation to richly describe the experience. Analysis continued through review of transcripts in individual meetings, collaborative review of narratives as a group, and journalling of the research process. Transcripts and tapes may be viewed as retellings of the experience of seeking help with a child with depression. Narrative analyses focus on discourse, on the tellings themselves as well as the context within which they are told (Polkinghorne, 1988; Sandelowski, 1991).

In this study analysis focused on data generated through one on one conversation, group conversation, and journalling. Attention was paid to the influence of voice, place, temporality, and multiple I's on the tellings and retellings of these stories of experience. Whose voice is being privileged? What tellings are silenced as well as spoken? How does environment influence experience and the meaning attributed to it? What parts of the narrative are past, present or future oriented? What does this suggest about the significance, value and intention of the story? And coming full circle, whose voice is dominant in the "I" expressed?

The researcher is oriented through three sets of methodological questions

(Clandinin & Connelly, 1994). Questions about the field of research experiences explore the reflexive relationship between living a life story, telling a life story, retelling a life story, and reliving a life story for the researcher as well as participants. Questions about the text told and written about the experience and its meaning are shaped by the relationships between the researcher and participants. Questions about the transition from field to research text are driven by questions about the meaning of the text and its significance. The final research text comes out of repeated questions about the meaning and significance of participants' stories, the threads, tensions, and themes, within and across persons.

#### **Ethical Considerations**

Prior to commencing this study ethical approval was received from the Research and Scholarly Development Committee of the Faculty of Nursing, University of Calgary. Participants were asked to read and sign a consent form if they agreed to participate in the study (see Appendices A and B). The consent form explained the purpose of this study and outlined their rights as study participants. Participants received a copy of the consent.

Participants were advised that their identities, in written transcripts, narrative summaries, publications, and professional presentations will be protected through the use of pseudonyms. Only the researcher has access to tapes which will be kept securely in the researcher's office. All tapes will be erased and transcripts shredded three years after the research project is complete.

Participants in group conversations were mothers who have participated in individual conversations with the researcher. The consistent use of pseudonyms was not be practical in extended group conversation. Consensus was sought as to whether participants preferred to be referred to by the pseudonyms used in the research text or by their real names. All participants chose to use their actual first names. Participants were asked to observe rules of confidentiality similar to those of support and therapeutic groups. Personal details and identifying information was not to be shared with others outside the group.

In narrative inquiry the potential exists to reshape both the participants' and the researcher's stories. It is therefore important that the researcher consider the experience that

brought her to this study, and the role that she plays in participants' stories (Clandinin & Connelly, 1994). Prior to engaging in this study I have explicated the assumptions that may be guiding inquiry. During data generation and analysis I have tried to explicate the role of my own experience and sought ongoing consultation with participants and the research committee. Journalling was conducted from start to completion of the research text.

I have an extensive mental health and counseling background. In my roles as Mental Health Clinician and Intake Coordinator I frequently speak with mothers seeking help with their children and am familiar with free and low cost mental health and counseling resources within the community. In the unlikely event that participation in this study would have aroused distress that did not resolve in the course of our conversations, the woman would have been referred to an appropriate resource while I remained available as a support during any required waiting time. This action proved unnecessary during the course of this study.

This study did not intend to be of direct benefit to participants. An intent of direct benefit for participants would presume that the researcher has expert knowledge of what would benefit mothers who have sought help with children suffering depression. This presumption is inconsistent with the values, beliefs and assumptions guiding this study. Literature on the therapeutic use of narrative frameworks suggests possible indirect benefits. The experience of sharing one's story may provide the opportunity to vent, as well as to receive validation and affirmation (Banks-Wallace, 1998). Opportunities for a sense of bonding or connection also exist, not only within the group setting, but also in sharing knowledge that may benefit others in similar circumstances (Cherubin, Flynn, & Morgan, 1998; Carey, 1998).

# Chapter Four

### Weaving a Fabric of Knowledge

This research text describes the threads, themes, tensions, and patterns within and/or across participants' stories. As such it may be viewed as a representation of the process of weaving a fabric of knowledge. The researcher's frame of mind influenced the initial focus on and attention to the threads or themes of describing a problem, negotiating the system, stigma and uncertainty within the women's stories. The narratives presented below reflect this framed awareness and thus are not raw or pure data, but the researcher's interpretation of taped and transcribed interviews.

These interpretations were taken back to participants for a further process of collaborative analysis. Through the process of collaborative analysis a more complex view of the threads evolved. Describing a problem was now seen as intertwined with discerning a pattern. Threads describing negotiating the system wound through and together with those describing nominating true supports. Stigma entwined with significance and uncertainty entwined with understanding. These threads could now be seen as interdependent filaments, nonhierarchically connected.

The intent of the process of collaborative analysis was to cocreate a relational narrative (Gadow, 1996) that honoured and included the voices of participants and researcher. Additionally participants were included in the process of considering the quality of the knowledge generated (Bailey, 1996). The reader of this text is also invited into this consideration.

# The Researcher's Frame of Mind

Any gathering and analysis of data, seeking threads, tensions, themes within the interviews would occur within the frame of my own attention, awareness, experience. The first interviews were conducted in the summer of 1999. The final text was written in March 2001. This final text may be seen as a narrative fabric made up of threads generated from participants' tellings of their stories in initial interviews; interpreted through the retellings of these stories in tapes, transcripts and collaborative analysis; and linked with threads in

existing fabrics of knowledge.

These tellings and retellings occurred within the frame of the research relationship. Initial tellings arose not only from the context of participants' experience but also from the researcher's curiosity and direct questions in first interviews. When and how did it occur to you to seek help? What did you do then? What does depression mean to you? Participants' responses invited the researcher to further reflect on the meaning contained within these stories. These reflections led to new questions, deepened the researcher's curiosity and led to further exploration of the knowledge woven through these women's narratives.

Earlier in this thesis the experience and assumptions of the researcher that led to the design of this study were explicated. Yet this final text is also a narrative, and as such, reflects the researcher's experience over time. The researcher's experience includes the research relationship, links made with other fabrics of knowledge and the larger context of the researcher's life in time.

During the time that this study was conducted I returned to my home community and my position as a Children's Mental Health Clinician. My daughter began formal schooling. My husband began a new career. My father succumbed to a terminal illness. I began to discern the presence of depression in my own life. These experiences influenced my participation in the research process.

It is my hope that these experiences may have deepened my understanding of participants' experiences. I recognize, however, that the same experiences that may have deepened my understanding, may also have narrowed my focus. In light of this I have endeavoured to hold in awareness the multiple I's that exist within my experience so that I may be more fully open and responsive in this collaborative research process.

# Whose Stories Will Be Woven Through

On reflection I realized that analysis began even before I met or spoke to the first participant. The process of selecting participants influenced whose stories were heard. Invitations to participate were extended to mothers who I spoke to at intake, met at a presentation to parents on childhood depression, and who were working with a rural liaison

person with the Mood Disorders Society. I did not aggressively pursue participants, but rather asked permission to send them a description of the study (see Appendices A and B) and followed up with those who indicated their interest.

Participant's ages ranged from 35 to 44 years. All were women seeking help for their sons whose ages ranged from 10 to 16 years. Two participants were married and living with the fathers of their children. Of the three single parents one was widowed, one separated and one a sole parent from the time of her child's birth. All sought help for their biological children. None identified themselves as belonging to a specific cultural group. None were visibly women of colour. Socioeconomic status ranged from two income middle class family to single parent living on social assistance. Three families elected to engage with formal children's mental health services. Two women utilized these services on a consultant basis only, as a part of their support system.

The following stories and the threads or themes emerging from them reflect the contexts of these participants. The experiences of younger women, women of colour, of diverse cultural backgrounds or who mother adoptive or foster children may include some of these themes but cannot be said to be represented in this study. Further research may broaden the fabric of knowledge to include their stories.

# Gathering the Threads: Narratives

The narratives below reflect experiences shared by participants in one on one interviews with the researcher. Information shared has been organized around a central story line and the themes that emerged in these initial conversations with participants.

Themes identified were: Describing a problem, negotiating the system, stigma and uncertainty.

Describing a problem refers to a process in time of relating the appearance or characteristics of a doubtful or difficult manner requiring a solution, something hard to understand or accomplish or deal with (Pearsall & Trumble, 1996). Tracing this thread within the mothers stories was not intended to result in THE definition of the problem.

Negotiating the system describes a process of finding a way over or through, a

complex whole, a set of connected parts, an organized body. (Pearsall & Trumble, 1996) Additionally it may refer to a process of conferring with others to reach a compromise within a prevailing political or social order.

Stigma describes the experiencing of a distinguishing labelling process. (Pearsall & Trumble, 1996) This process may be experienced as a mark of disgrace. Uncertainty describes encountering the unknown. The experiences of stigma and uncertainty may be considered as threads that cross and join with threads referring to the processes of defining a problem and negotiating the system.

Although the story of this study has a beginning, middle and end that can be seen by the reader, the endings of the stories of these women's experience is not contained within the confines of this thesis. These lives continue to be lived, the seeking of help continues in the social context of these women's lives. These are stories of women in the middle of seeking help with their concerns about their children. Through the tellings contributing to the stories contained here these women begin to give meaning to their history and ongoing experience, hoping to influence and shape the story yet to come.

These following stories illustrate the middle of the story of this study. The threads discerned reflect the researcher's initial understanding of the knowledge contained within the mothers' experiences. As the story of this study continues threads or themes reviewed here will be reconsidered in light of the process of group analysis and connections to other fabrics of knowledge.

### Anna's story.

Anna and her husband Tom live with their three children - Laura, 15, Steven, 12, and Jeremy, 10 - in their own home in a newer suburb. Basketball hoops stand off to the side of newer model cars and vans. Shrubbery and lawn decorations colour the yards among young trees. Tom and Anna's home occupies the inside curve of a bay that parallels the main road marking the city's eastern boundary. Both work outside the home, Tom as a technical service worker, Anna as a paraprofessional in a separate school.

Anna spoke with me about her experience seeking help with her son, Jeremy. We

met at my office, a coffee shop in her neighbourhood, and briefly at her workplace. We worked through further interpretations in telephone conversations from our homes and workplaces.

Jeremy, Anna's youngest child, had been a fairly shy and quiet child. He preferred hopscotch to competitive team sports. His older brother, Steven, had been a more active and risk taking. Anna observed these as differences in temperament evident from infancy.

Anna and her husband, Tom, had become accustomed to receiving calls from their neighbourhood school about Steven. In dealing with the school's expressed concerns about Steven's disruptive behaviour Anna developed knowledge about the resources available within the school system. She faced pressure from the principal and Steven's classroom teacher to collaborate in behaviour management strategies that isolated Steven from his peers and reduced his opportunities for social and academic success. With the support of the school counsellor and social worker Anna advocated for strategies that would facilitate Steven's success at school. He received a diagnosis of Attention Deficit Disorder (ADD), began medications, and learned to use self initiated time outs to visit the counsellor when he had difficulty focusing in the classroom.

When Jeremy's behaviour at school became a concern, school personnel made comparisons to his older brother. The principal suggested that a psychiatric assessment was warranted to determine whether Jeremy also had ADD. The classroom teacher began to separate him from peers for his aggressive behaviour on the school grounds.

Jeremy complained that he was being teased at school. Anna's husband and her father believed that these were things Jeremy would simply need to learn to deal with. Anna wondered if she may have contributed to Jeremy becoming a target for teasing. She reflected that "you tend to baby the younger one a little bit longer because you know it's your last one and...I have babied him. Maybe he's having a hard time accepting...that this is just what life's all about."

This wondering supported the opinions voiced by Jeremy's teacher, father, and grandfather. Jeremy lacked social skills. The solution was to encourage Jeremy to change his behaviour. Anna and Tom instructed Jeremy about appropriate responses to teasing. If

Jeremy behaved inappropriately on the school field he would remain in the classroom at recess. For a brief time, Anna noted, Jeremy's behaviour at school was more controlled.

At home, however, conflict between Jeremy and Steven was frequent and dramatic. In the context of this continued conflict Jeremy's reactions led Anna to a description of a problem that led her to seek help. Anna felt frustrated in her attempts to manage this conflict as she seldom was able to observe the process but only the outcome. As she described it "All hell would break loose. Jeremy'd be screaming at Steven and Steven'd be screaming at Jeremy. Eventually Jeremy said to me something to the effect of I might as well just die."

Jeremy's statement that he might as well just die marked a major turning point in Anna's help seeking experience. She described it as a red flag. This statement linked Jeremy's present behaviour to Anna's family's history of depression and raised fears for the future. Anna's brother had committed suicide eight years earlier. Not until after his death did Anna learn that her brother's wife had observed changes in his sleep, appetite, mood and behaviour for three weeks prior. These changes were echoed in Anna's observations of changes in Jeremy's sleep, appetite, mood and behaviour over the past year. Anna was compelled to negotiate the system seeking help for Jeremy.

Educators played a significant role in Anna's attempts to negotiate the system. Her experience with the school system was not one of contact or connection with "an organized body... a set of connected parts (or) a complex whole" (Pearsall & Trumble, 1996). Rather she experienced some individuals as sources of support and others as sources of further stress.

Relationships with the principal and Jeremy's classroom teacher were experienced as sources of additional stress. Anna felt that Jeremy was singled out for punishment and that her concerns about this were not recognized or addressed. Jeremy's teacher managed his reactions to peer teasing by removing him from the playground at recess for the last two weeks of school. When Anna attempted to advise the teacher about her concerns that Jeremy may be depressed, the teacher shared her view that depression was simply anger turned inward. The principal did not support Anna's request that he be placed in a different classroom from his two primary tormenters for the following school year. During the initial

research interview Anna was considering how to elicit support for the desired change. By the time of our second meeting Anna had enrolled Jeremy in a new school where she experienced a sense of collaborative partnership.

Anna identified the counselor and social worker at Jeremy's original school as sources of support. The morning after Jeremy expressed his thoughts of suicide Anna accompanied him to school. She encountered the counsellor in the hall and asked for a few minutes of her time. As the office door closed Anna burst into tears and said she needed help. The counsellor met with Jeremy and heard his distress at being teased by peers and the adult responses to his reactions. She offered to work with Jeremy and his peers as a group but did not follow through with this action. With some resignation Anna expressed her understanding that the counsellor's workload may have dictated other priorities. The school social worker supported Anna's expertise about her own child. Anna felt commended by the social worker for recognizing that Jeremy had a problem and reassured that she and Tom were not to blame for this.

The school social worker and the counselor suggested links to the health care system. Initially the counselor had recommended contact with their general practitioner. After conducting a complete physical examination the physician reassured Anna that childhood depression was common and treatable with medications. The social worker recommended contacting the community's Children's Mental Health agency.

Connecting with Children's Mental Health was not an end, but a continuation of negotiating the system. When Anna received a call from one of the agency's intake clinicians, five days after her initial phone call, they discussed concerns that she and the school had about Jeremy. The clinician suggested the school do an initial assessment, given the question of ADD. Anna called the social worker and was advised that this was unlikely to happen in the two weeks remaining in the school year. The social worker referred her back to Children's Mental Health. So Anna called back to Children's Mental Health and asked the intake clinician to call the school directly. After the clinician spoke to the school social worker she called Anna back to schedule an appointment for a psychiatric assessment at Children's Mental Health two weeks later. From this meeting the psychiatrist gave a

diagnosis of depression and sent recommendations to their family's physician recommending treatment with antidepressant medication.

What had it been like, I asked, to participate in this process and to hear the diagnosis. Preparing to attend the assessment, Anna reflected, Jeremy had cried, he thought he was in trouble, that he'd done something wrong. As for herself, she continued, she wasn't surprised on ultimately hearing a diagnosis of depression. But she was very upset, and didn't know if she had fully accepted it. Her description of her response echoes Jeremy's feeling of having done something wrong: "Sometimes you think that maybe it's something that mom and dad could have helped him work through a little better...I feel awful that he's only 10 and he's going to be taking medicine like that."

She spoke of the story of depression in her family. Her brother committed suicide following an apparent depressive episode. Her maternal grandmother also, in Anna's words "had two nervous breakdowns. In those days they did the shock treatments. She's had them twice." Anna's mother, in Anna's opinion, had likely also suffered depression although she is not aware of her receiving a diagnosis or medical treatment.

Anna's family story and her response to hearing a diagnosis suggested threads of isolation and stigma. In light of this I asked who was the news of Jeremy's diagnosis shared with? Jeremy had asked Anna not to tell anybody, even his grandparents or siblings. Anna felt that she should tell her parents but worried about their reaction. Her father in particular, she felt, would reject the diagnosis itself as craziness. She anticipated a response from him that Jeremy simply has to grow up, learn to behave and accept that he will be teased. His brother and sister were simply instructed to be more gentle with Jeremy. Anna also struggled with deciding how much to tell the school. She recognized that sharing this information would be a natural part of establishing supports. Yet her experience working with the principal and classroom teacher caused hesitation. Why, she wondered did she have to open her family's experience to people from whom she anticipated judgmental responses that would serve to increase stress rather than supports available.

Anna has shared the news of Jeremy's diagnosis with two people who she identified as sources of support. Her next door neighbour is aware. But Anna's ability to speak with

her about her experience is limited by the fact that Jeremy's siblings have not been told. When Anna and her neighbour have time together it is generally with their children near by. One of Anna's friends in particular has been told and is a source of support for her. This friend has suffered a major depression herself and shares Anna's belief that receiving treatment is helpful.

My first conversation with Anna occurred shortly after Jeremy and Anna met with the child psychiatrist for an assessment. Their follow up appointment with the family physician was still one week in the future. A diagnosis had been received, a specific treatment recommended. At this point Anna reflected that the the whole help seeking process didn't take very long. Anna had found out about this study through the Children's Mental Health intake clinician. On referring Anna, this person had described the study's focus as looking at service provision. Although I thought I had clarified that the focus was her help seeking experience I still had wonderings.

Did Anna see the whole process as complete? Was her comment influenced by my dual roles? I also work as a clinician for Children's Mental Health. Perhaps the setting of our meeting influenced her understanding of what I may have wanted to hear. Our initial conversation took place in my office, located in the same building in which Anna and Jeremy met with the child psychiatrist and received a diagnosis. Did help seeking end with a formal definition of the problem and a recommended solution?

Was seeing the whole process as complete a coping strategy, a way of managing uncertainty? Looking back Anna believed that Jeremy's acting out at school led her to take action about concerns that had been developing over the year prior. Looking ahead she hoped that treatment with medication now might reduce the risk of a more serious depression developing in his adolescence. Yet fear of suicide overshadows her view to his adulthood.

My last conversation with Anna was just prior to the final meeting of researcher and participants for collaborative analysis. We spoke by telephone. The family was at an especially challenging place in their experience of living with depression. Jeremy was again expressing suicidal thoughts.

I agreed with Anna that actively engaging in help seeking at this point, was, for her, a higher priority than reflecting on the experience of help seeking. During the time we had worked together, the multiple demands in both our lives had led to missed and rescheduled meetings. At one meeting, at a cafe during the Christmas season, we had reflected on the challenge of maintaining boundaries that allowed time for self care in the midst of the demands placed on us in our multiple roles. I shared with Anna my sense of understanding that electing to forgo this group meeting was her response to this challenge.

### Brenda's story.

Brenda spoke to me of her experience seeking help with her son, Todd. Todd is 12 years old and the youngest son of Brenda and her husband Craig. His older brother Daryl is 14 years old. The family home is located on a bend in a suburban bay at the southern limit of the city. The rear of the home overlooks the playing fields of the local elementary school. Brenda runs a home based child day care and teaches parenting workshops at the local family resource centre. Craig is employed as a sales manager, a position that requires frequent travel.

Brenda's story traverses a five year journey through a maze of helpers and varying descriptions of the problem. At points the story line of journey became tangled and difficult to distinguish even to Brenda herself. The one central organizing theme that emerges is her effort to unthread the maze and manage their lives in the presence of Todd's depression.

His mother believed that, in Todd's third year of school, bouts with tonsillitis and his subsequent absences from school excluded him from the core social group. His self esteem was suffering. He started to put on weight. He developed friendships with "the outcasts".

His first friend was a streetwise classmate living in a foster home. Ultimately this boy got into so much trouble that he was physically removed from Brenda's neighbourhood. Brenda went on to describe that her son then connected with a boy from another part of town attending the same tutoring program. She supported this friendship by driving Todd to this boy's home. Subsequently she discovered that supervision there was

such that the boys had access to materials to make cherry bombs "rolled up toilet paper dipped in gasoline and wrapped in paper". She explained the dangers of this practice to him and that she could no longer support this relationship.

Brenda was compelled to seek help when the next day after school Todd entered the house smelling of gasoline. She shared with me her belief, arising from her participation in voluntary community resources, that "there are agencies or people out there that can help you. All you have to do is pick up a phone and people will come and help you." She called the fire department and was put in touch with one of their public relations representatives. He asked Brenda and Todd to complete a questionnaire, and then spoke to Todd alone. Following this he suggested to Brenda that Todd could be assessed by a psychiatrist at the Children's Hospital.

Todd's arrival home doused in gasoline had raised understandable safety concerns for Brenda. Given this is seemed prudent to pursue all avenues of investigation. Brenda initiated contact with Children's hospital's department of psychiatry, the first step in a long journey through the health care system.

At the Children's Hospital Brenda and Todd met with a team that included a psychiatrist, a psychiatric resident and a nurse. Both she and Todd found their questions upsetting, accusatory in nature. "It sounded like he was a budding arsonist...(and Todd) was like, 'mom what are they talking about?"" Ultimately the team agreed with Brenda and made a referral to Children's Mental Health to help Todd with his self esteem.

It was at this point I first met Brenda and Todd. Todd was eight years old. I was the assigned clinician with Children's Mental Health. Our contact was brief. After three therapy sessions Brenda, Craig and I agreed that concerns about Todd seemed to have subsided with the ending of these two friendships.

Negotiating the education system also figured prominently in Brenda's help seeking experience. Beginning with his grade three teacher Brenda and Craig received reports that Todd did not listen in class, and seemed to require a very structured approach to engage his attention. His assigned teacher for grade four had a reputation for providing very clear expectations. By October of his grade four year, it became clear that Todd was miserable.

Brenda related to me the frustration Todd expressed: "The expectations were too high, he didn't fit in, life was just too hard. He was crying saying there was no sense even living anymore."

Although Brenda suspected that Todd's distress originated from his school experience, Todd was unwilling to talk about this. In light of the information that Brenda received from Todd's classmates who also attended her home day care Brenda wondered whether Todd's reluctance to talk about his teacher was akin to abuse victims' internalizing responsibility for the behaviour of the abuser. Todd's classmates described the teacher's behaviour in terms that clearly sounded abusive. She ripped up unsatisfactory work and called them stupid. When parents had spoken to the teacher about this in the past, their child was singled out in class the following day, Todd's classmate's reported.

Attempting to elicit support, Brenda spoke to other parents. In the face of their reluctance to confront the situation, Brenda chose to approach the school principal. The principal offered to meet with Brenda and the teacher together. The teacher, in the principal's presence, advised Brenda that she placed high expectations on children and those who could not measure up were weak. She would not respond to complaints made by other people's children. The only resolution that occurred was a memo sent to parents that differences with teachers should be resolved directly with them before approaching the principal.

Brenda resolved to influence the selection of Todd's grade five teacher. From her experience volunteering at the school and in supporting her older son's education, she knew which of the two grade five teachers she preferred for Todd. She had been told by the principal that parents were allowed to make only one specific teacher request in their child's school life time. She made her request in March and assured Todd that he would not have the "dragon lady" for grade five. Yet he opened his report card on the next to last day of school to find that this unagreeable woman was exactly who his teacher was to be.

In our conversation I wondered whether Brenda saw this apparent miscommunication as connected to her meeting with the principal and Todd's grade four teacher. Brenda was visibly angry as she shared her belief that she was in a sense being

reminded who had the power in the school culture. She related how she called the school the morning after Todd received news of his teacher assignment. She was told there was no record of her request. She went to the school directly to speak with the principal. She was kept waiting in the school office until five minutes past dismissal time and received what she felt was the thinnest of apologies. Sorry, the request must have been misplaced, she was told.

Although Todd was eventually placed with the requested teacher his experience at school was still a source of stress. Again it was one of Todd's classmates who initially let Brenda know how things were going. The children were feeling a lot of pressure to prepare for an upcoming provincial math examination. Brenda believed the teacher was also under pressure to produce strong results. Todd just wasn't absorbing the material. By May the teacher told Brenda she'd given up on him. In this context he began to behave disruptively. Even getting him to school was difficult. The teacher responded by sending him to the school counselor.

This was the same teacher who Brenda had experienced as an exceptionally good teacher for her older son Daryl. Brenda understood this as a function of Todd's and Daryl's differing temperaments and needs. Craig understood this as Todd not measuring up to the standard set by his older brother. Tensions were rising at home. Brenda described the situation to me.

By the spring of grade five I was very much between Craig and Todd keeping them from each other's necks. Todd was heavier (than Daryl), not doing well in school, getting foul mouthed... At that point Craig really felt Daryl was the golden child.

Brenda was hesitant to take up Craig's suggestion of family counselling. She had come to feel responsible for containing conflict and hostilities within the family. She was afraid that airing them was potentially hurtful. From this point Brenda's recall of events and their sequence became less clear. She explained:

Somehow this is reminding me of giving birth because I can't remember the fights or anything. Actually even with this whole situation, with the whole depression thing, I was able to tell the story so well to all these professionals and it's like somebody put an erase button in there and erased a lot of the bad stuff and I'm finding I can't put together the

stories as well as I could before.

Approaching a crisis in her experience challenged her ability to make meaning with the many demands pulling her out of the centre of her story.

Brenda identified one day in particular as a pivotal point. Craig had arrived home with a promotion and a bonus. He offered to buy each family member a gift to celebrate. He offered to replace a team hat that Daryl had lost. Todd insisted that if Daryl got one hat he wanted two. He was not going to go back to school until he got two hats, he stated, retreating to his room and his rocking chair. Brenda followed hoping to convince him to return to school for the afternoon. As Brenda spoke Todd rocked and tapped his foot against the wall. Brenda saw this as testing, looking for a reaction. She believed he was surprised when he put a hole in the wall. Craig saw it as intentional, willful damage.

Telling Todd that he had to go to school, Brenda left the scene at home. She was going to discuss this with the counselor. By chance, she found him in the school field, directly behind her back yard. In tears, and distressed by this visible sign of loss of control, she described her situation. The counselor offered that family counseling did seem needed to get her out of her bind. Tell Todd to come to school, in say, half an hour and everything would be fine, he added. Todd's behaviour at school improved once there was agreement on the goal of simply getting him through attending the remainder of the year.

Hesitantly Brenda made arrangements for family counseling. She put off making an appointment and then canceled the first one booked. Brenda and Craig attended the first session and described their home life. They were told that the children, Todd in particular, had too much power. This did not sit well with Brenda. Neither Daryl or Todd were impressed when, at the second meeting, the counselor explained the concept of a family hierarchy with parents on top and kids underneath.

After meeting Todd the family counselor shared her concern that there might actually be something wrong with Todd, something treatable. The counselor arranged an appointment to see a pediatrician within two days, a child psychiatrist within the week. Out of this came a diagnosis of depression, a prescription for an antidepressant medication, and a recommendation for weekly therapy.

Initially Brenda felt somewhat relieved. Receiving a diagnosis of an illness relieved the burden of feeling blamed. Naming an illness was experienced as explaining Todd's behaviour and some of the family conflict. Although contact with the family therapist had led to the diagnosis of depression Brenda didn't feel it had been especially helpful otherwise. The focus on family structure was experienced as widening the differences in Brenda and Craig's parenting styles, and supporting the opinions of extended family who assigned blame to both Brenda and Craig.

Brenda's sense of relief was short lived however. Her help seeking experience did not end with receiving a diagnosis and recommendations of treatment for Todd. Brenda often wonders whether the prescribed treatment created more problems than it was proposed to solve. Todd started on antidepressant medication in September. In November Craig and Brenda took a vacation while the grandmothers cared for the boys. Brenda's mother, who had personal experience with depression that included receiving shock treatments as a young woman, phoned Brenda at their vacation accommodation. She was calling to advise Brenda that she was concerned about Todd's changing, increasingly agitated behaviour and was calling the doctor to stop the medication.

Brenda accompanied Todd to the pediatrician's office on her return from vacation. She felt that he did not hear her concerns about the effects of the medication. He was increasingly moody. He was intolerant of heat. He was uncharacteristically energetic in gym class at school. He had assaulted a classmate. He had begun to be physically assaultive toward her. On one instance Daryl had had to physically restrain Todd from further striking his mother. The pediatrician had lectured him to listen to his teacher and be nice to his mother. On Brenda's insistence the pediatrician checked Todd's blood pressure, then concurred that this medication should be stopped. Another medication would be tried.

On stopping the first medication Brenda called Children's Mental Health and then filled the new prescription. About a week later, Brenda told me, a clinician from Children's Mental Health called to say that one of their psychiatrists, whom Brenda and Todd had not met, wanted all medication stopped pending an appointment one week later. This psychiatrist diagnosed Todd with a bipolar mood disorder. He wanted him to continue

without medication until their next appointment, about one month later. By this time, just after Christmas, Todd was very depressed and suicidal. Brenda considered sprinkling Lego in the hallway overnight so she could hear if Todd was leaving his room.

Throughout all of this Todd continued to attend school. Brenda did not consider doing otherwise because he was not visibly sick. He couldn't concentrate or do any school work. His teacher considered Todd's problem to be behavioural, not illness related. When he was depressed he was not disruptive. The school now had a new principal, who had taken a liking to Todd. The principal, counselor, and Brenda agreed that this would be a "lost year" academically but that Todd would continue to have the structure of attending school.

While awaiting the next appointment with the psychiatrist Brenda contacted the Mood Disorders Society. By chance the Mood Disorders Society was sponsoring a presentation by a psychiatrist on the topic of bipolar disorder, just two days after Todd had received this diagnosis. Craig and Brenda attended. She became tearful as she related the experience to me.

That was a very bleak talk...I asked...was he just suffering depression and the drugs have created mania or was mania always there and the drugs have just unmasked it and...How long does this last?...When he said that children who are diagnosed with bipolar disorder by the age of ten have it for a life time, and that there's nothing short of drugs to take care of it for a whole life, and he can pass it on just like it was passed on to him..I mean two days before you're told this is what he has...two days later it's like holy Christ he's got it for life!...And, and he needs a placard on him so people know, I mean if he had crutches, or a cast, perhaps they'd understand it but they don't, just, I mean, he's just an odd duck. It's, it's not fair to him...Every bloody medication now has put him over the edge. He's gained more weight. He's just a little guy. He's being called fat psychonut. I was rather distraught...Everything was so overwhelming. I couldn't believe that the little kid I loved so much kept wanting to hurt me.".

The information received at this presentation, from a doctor who did not know Brenda, her child or their family's experience, was a major source of stress, stigma and grief. The Mood Disorder Society served as a support in other ways. A male staff member she spoke to assured her that she was dealing with an illness and not an abusive child. He introduced Brenda to a female staff member with a special interest in bipolar disorder in children. Brenda found her very helpful, as moral and practical support. Brenda could speak freely with this woman. She also gave a presentation on childhood bipolar disorder to the

entire staff at Todd's school.

By March the treating psychiatrist observed that Todd's bipolar illness was one with rapid cycles, quickly moving between highs and lows. He suggested starting Todd on a mood stabilizing drug in addition to an antidepressant. He mentioned that weight gain could be a side effect. Todd was very reluctant. The psychiatrist stated that at this point the other alternative was hospitalization. Todd's response was that he had no friends and no reason to live so he may as well be in hospital. The psychiatrist advised Brenda that he intended to admit Todd to Children's Hospital psychiatric unit for six weeks to stabilize his medication. Brenda responded to this development with shock and disbelief. She described her attempts to come to terms with this news.

The thought of losing him for six weeks to a hospital...I thought something had to be seriously wrong before he would be admitted to hospital, not just up and down kind of stuff...He hasn't actually hurt himself...I started to cry...his clinician was there and said maybe Todd thinks it's best to do...get this taken care of...Yeah, Todd just thinks he has a test on Monday and just doesn't want to write it.

Admission to Children's Hospital meant a change in the team managing Todd's care. Brenda did not experience this as a smooth transition. There seemed to be little agreement on treatment goals from one team to another. Even seemingly small concrete details such as when Todd would be admitted or how long his anticipated stay would be were presented very differently by the psychiatrist at Children's Mental Health and the staff at Children's Hospital. Yet another psychiatrist was responsible for Todd's treatment at Children's Hospital. He diagnosed Todd with major depression and oppositional defiant disorder. He did not concur with the prior psychiatrist's diagnosis of bipolar disorder. He explained that a diagnosis of oppositional defiant disorder meant that Todd needed structure and firm rules. Brenda experienced this statement as a criticism of her parenting.

Three psychiatrists had provided in total three diagnoses. In the face of this lack of certainty Brenda began to develop her own sense of expertise. She was animated and expressive as she spoke of this.

I'd already read everything on depression, hipolar disorder and was so darned depressed from reading depression things that I figured give me a Cosmo I've had enough! And then I had to find oppositional defiant disorder. There's very little on that...all

it says is that..ends up turning into conduct disorder...that is worse ...they go in the slammer at that point... (Then) they say oh well they didn't get help. He's getting all this help. We've got all these people kind of helping us.

Although Brenda's story contains a large cast of helpers it was essential for her to assume a central role in coordinating efforts. The psychiatrists at Children's Hospital assumed that the treating psychiatrist from Children's Mental Health would continue to follow Todd's case once he was discharged. Yet the psychiatrist at Children's Mental Health told Brenda she would need to find another child psychiatrist. His case load only allowed him to see Todd every six weeks. When Brenda asked if he had any particular names the psychiatrist suggested that Todd's clinician could phone his secretary for a list. The psychiatrist's secretary had no names to suggest. As Brenda simply phoned around on her own she was told that the medical community was failing her. She should not be phoning around trying to find your own child psychiatrist. Her child should have had a psychiatrist dealing with him on a full time basis long ago. These were the words of psychiatrists she spoke to including the psychiatrist at Children's Mental Health.

By chance an acquaintance knew of another family whose son had also been diagnosed with bipolar disorder. Brenda called and was given the name of the psychiatrist their son was seeing. She hesitated to call him though. This boy's family was really struggling with his illness. Brenda reflected.

I just hope I don't experience that or if I do I want to go in with blinders so that I can take each day at a time instead of dreading it ahead of time...I asked what her impressions were (of their son's psychiatrist) and she's well I don't know...they can do all the talking in the world they want but it's not changing much.

This other family had been directed to their child psychiatrist by the same school clinician who was dealing with Todd's family on a weekly basis. After contacting the school clinician and hearing her recommendation Brenda called him to schedule an appointment. This psychiatrist shared his opinion that their consultant psychiatrist at Children's Mental Health was probably the best resource on bipolar disorder. Should this latest psychiatrist take on Todd's case his approach to treatment it would also mean that the family could no longer maintain their connection with their clinician at Children's Mental Health. It would

be a duplication of service. At the time of my first conversation with Brenda no definite decision had been made and services continued in place through Children's Mental Health.

During one meeting with the consultant psychiatrist at Children's Mental Health he commented on Brenda's note taking. He described it as a common coping skill for adults suffering Attention Deficit Disorder. She did not appreciate the comment, describing her thinking as: "I managed to get through life. I've got two degrees. I just take notes, thank you very much." On finding a brochure on ADD in the waiting area, she picked it up and noted that indeed the descriptors of positive traits of persons with ADD sounded a lot like her.

She took out more books on ADD. In the sections on women and ADD she noticed that the description of the type of men they may tend to marry also sounded fairly accurate. As she read on she found that in children the symptoms of ADD and oppositional defiant disorder were quite similar. With this information she concluded "to hell with this oppositional defiant disorder stuff. I pretend that it doesn't exist...(W)ith bipolar disorder ADD is part and parcel of it." The consultant psychiatrist agreed with her. He suggested a trial of Ritalin. It would help with school and was short acting. The school agreed. Brenda described her sense of developing control and optimism to me. "We went home as happy as larks. That little bottle, we're going to now solve all of Todd's school problems."

A trial of Ritalin was begun that weekend while Craig was on a fishing trip. After experiencing thirty six hours in which Todd became increasingly agitated, got into fights with friends, and did not sleep, Brenda decided to stop the medication. She waited until Monday to discuss the situation with his clinician at Children's Mental Health. They lived with his erratic moods and sleep disturbance for the next week.

At no time in this experience did Brenda consider using crisis resources such as the Mobile Crisis Team. To her this action meant she was giving up on her child, sending him away. She communicated her belief and its origins to me.

<sup>&</sup>quot;I always have this awful feeling they're going to take him away...Craig's so quick to call these people...cause the family counselor said we don't have to deal with this.... this is our life... we have to learn how to deal with it. When it's one of our lives are in danger, then, no, we can't deal with it. But at the moment if we are going to have to deal with

mania and depression on a day to day basis, then we better learn how to deal with it...

It's selective help I want...At the hospital they said eventually you know...well (the family counselor) said it first. Eventually, you know he might just have to be taken away because you can't let him destroy your family. (And at the hospital) the psychiatrists said that well if this thing turns into conduct disorder, you're just going to have to ultimately send him away. And I just looked at the men and said that will be our absolutely last resort, because he's not being sent away. And every time I say that I can just feel a spike going down between Craig's and my relationship."

By the time of my second meeting with Brenda, Todd was attending a day treatment program at a residential treatment facility affiliated with Children's Mental Health. He attended school at the treatment facility and was learning new coping skills. A new psychiatrist assumed Todd's case as part of this program. Todd had been on no medications for four months and both his weight and mood swings have been reduced. Some changes have occurred in the family dynamics. Craig has become aware that this illness could end Todd's life. This awareness is perhaps has allowed more communication between he and Brenda about their sense of loss and grief.

On reading other participant's stories, particularly those who did not engage with formal helping systems, Brenda wondered aloud whether she should have simply managed the situation on her own. She believes, based on her experience, that the medications offered as solutions only worsened the problem. She found the family counseling sessions the hardest part of her help-seeking experience as felt that she was being described as the problem, but was able to hear from Anna that for her the coping strategies learned likely preserved her marriage.

Brenda continues to keep abreast of publications about childhood mood disorders. Parent support groups are helpful, Brenda noted, especially in overcoming the sense of isolation and stigma that accompany living with depression. However, her experience has been that they tend to drift apart due to the multiple conflicting demands on members' time. Brenda continues to balance the many demands on her own time. She was unable to attend a final participant group meeting due to attendance at classes both as student and instructor. But she maintained a keen interest and her comment: "Fax me, email me, voice mail me, phone me, keep in touch," suggested multiple ways of connecting to overcome the obstacles otherwise imposed by multiple demands.

#### Cheryl's story.

Cheryl related her experience seeking help with her son Mark, aged 12 years.

Cheryl had been sole parent to her only child for one year after Barry, her husband, Mark's father, committed suicide. Cheryl is employed as an administrative assistant for a government agency. The family lives in a cozy condominium suite in a complex near the city's north eastern edge.

My first contact with Cheryl was in my role as Intake Clinician when she called Children's Mental Health to request service for Mark. Mark had seen one of the Children's Mental Health clinicians following his father's suicide almost exactly one year earlier. This connection had been established through the facility that had been treating Barry for depression. This time Cheryl phoned immediately after being informed by Mark's school that he had been talking about suicide. The very real fear of suicide prompted her to move quickly.

Curiously, this was not the first time that Mark had spoken of suicide at school. It was the third time. But it was the first time Cheryl was called. The first two times, he had said that he didn't want to live, that he should be dead, to one of the teachers. He was sent to see the school counselor. The third time, after he had made a similar comment to a friend, was when the counselor became concerned and phoned Cheryl.

Cheryl felt anger and fear that she had not been told at the first disclosure. She recognized that the counselor was responsible for over a hundred children. She understood that the school may not have recognized the seriousness of the situation until Mark spoke to other children. She described her response with, what I thought was, remarkable calm. "It's instant fear for me because I've experienced death by suicide...The safety of my child is the most important thing to me. I've expressed to them that I want to know..whenever it happens."

The lapse in communication from the school was especially concerning because Mark's behaviour at home gave no clues to his distress. All the misbehaviour occurred at school. Cheryl shared her feeling that Mark may have been afraid to tell her of his feelings, that he didn't want to burden her further. Once the disclosure was made and she was able to

talk with him he shared his feeling that he wouldn't be a burden to her if he was dead. She made it clear to Mark that she needs to know what he is feeling, even if it may upset her.

Once Mark had connected with a clinician, Cheryl phoned the counselor at the school to advise her that this was now in her hands. She described this to me as she said, "I find I have to keep on top of them to ensure what I need to have done is done." She phones the school counselor to keep her abreast of how Mark is progressing in therapy and to ask how he is doing in school. As a result of her actions Cheryl described feeling that "I'm a part of this now. I know what's going on. I'm not being left out. I made a choice to do it, I had to do it."

Upon receiving the information from the school Cheryl knew how to negotiate the health care system. She cited her prior experience as a resource as she told me "In dealing with Barry, that's where I initially found resources, so I knew where to call for my son."

Cheryl and Mark attended a grief support group at their local hospital. She consulted with the psychologist there when she received the information from the school. He suggested that Mark should undergo an assessment for depression. She also consulted with the psychologist about how to broach the subject with Mark. She didn't want to simply announce that he had an appointment for an assessment. She was sensitive to the effects of stigma and that Mark might feel that he was just like his dad. She agreed to give Mark a choice by simply asking whether he would like to talk to someone about these feelings. She was confident that Mark would agree.

Cheryl had a strong sense of herself as an expert about her child. She took action to access and arrange resources by calling Children's Mental Health and determining how quickly Mark could be seen before she offered the choice to him. She was clear about what help she wanted for him and herself. The psychologist at the grief group had suggested that Mark could access help through Children's Hospital. Cheryl chose to return to Children's Mental Health assuming that their prior connection could mean a quicker understanding of the situation and therefore quicker access.

Cheryl's prior experience of depressive illness, with her husband, heightened her sense of fear. For her depression was a potentially life threatening illness. Fear of suicide mobilized Cheryl. She needed to act now regardless of any sense of uncertainty or guilt she may have had. As she told me:

At one point I didn't know what part was grief. Because depression is a part of grief. Or were we dealing with depression in Mark?... I had feelings of, here is Mark without a dad..look what I've done to him. Because...it was my choice to be married to this person, however, it wasn't Mark's choice to grow up without a dad...Even though I might feel ashamed or guilty, the feelings I'm dealing with, that doesn't deter me from getting the help that Mark needs. I'm just doing what I need to do NOW, cause that's all I have, is now.

Focusing on the action she can take in the now is a source of hope for Cheryl. This focus on what she can do now includes an awareness of what she can not do. In accessing help for Mark now Cheryl enacts her hope that Mark will learn to cope with his emotions and experience life as worth living. She has learned from experience that only Mark can do what he needs to do. She could not stop her husband's decision to commit suicide, she reflected. Although it is painful for her to see Mark in distress, she believes that he will not learn to cope if she assumes responsibility for his feelings and tries to take his pain away.

The role depression will play in her son's life is a remaining uncertainty for Cheryl. With her husband she experienced it as a deceptive life threatening illness. At the time of our first conversation Cheryl managed this uncertainty with an awareness of the limits of her own power. She explained the impact that this has for her now in her experience with Mark:

"I have this sense that I don't know is it going to be okay or not. Cause the way depression works...my husband could be fine it's like they were, how can I explain it? Talking to each other face to face and I believe what he's saying, however it could be the illness intertwined with that? So it's like you're not really sure where the person in the illness starts. That's what I feel with Mark if he's saying to me yes mom. I'm okay mom. And can I trust he really is okay?...I'm doing all I can to help Mark and that's all I can do...I talked to my husband the night before...and in the morning..we were at the hospital and he was dead. So that's where that part that I don't feel as comfortable with, that's where I need to bring in, I put my faith in God's hands and I just have to leave it there. And that's where my powerlessness is, is there.

Looking forward Cheryl's biggest question is whether Mark will survive the presence of depression in his life. Her strength she says comes of necessity, being his sole surviving parent. She draws on the support available in her connections with friends, family, her counsellor and her church. Being able to pick up the phone, talk, and just hear their care

keeps her going, she said, when things get tough.

Looking back Cheryl saw that these supports were there through her husband's illness but that she did not connect with them. In trying to be a total support for him, she reflected, little time was left for herself or Mark. Since the time of her husband's death she has made time to see a therapist for herself. Her therapist has also experienced loss through suicide. This sense of shared knowledge, Cheryl feels, makes this a particularly powerful connection.

If given the chance to connect with other mothers seeking help, I asked, what knowledge would she share or seek? She paused briefly and then responded.

I'd look more at the behaviour than listen to the words. (With) Mark I can tell on the days when he continually eats and he knows too. He says mom I'm just eating my feelings away...that's a coping mechanism...to try and get rid of the pain.

At the time of my first meeting with Cheryl, she was still in the process of working with the school to deal with his behaviour and to distinguish its connection to grief and depression. He had been suspended from school twice in the past three weeks. She expressed frustration that the school seems to simply expect him to behave appropriately without extending any effort to understand his behaviour. One teacher in particular, she found on meeting with him to discuss Mark's behaviour, bore a striking physical resemblance to Mark's father. She felt, she told me, that the school needs to "look at the grief, that he's grieving. It's not over in a year, grief is not done." She questioned the effectiveness of behaviour management techniques that remove privileges or isolate the child. What is the meaning, she asked, of these consequences to a child who has suffered an enormous loss? What, she wondered, does this teach?

At the time of my first conversation with Cheryl, she was actively engaged in accessing and maintaining supports for herself, for Mark, for the two of them together.

Almost one year later, reading a draft of her story, she smiled, sighed and remarked on what a long way she had come since then. As we spoke, Mark was heading out the door with a sled and a friend. She and Mark had returned from bowling. As this meeting drew to a close, I offered to deliver the revised draft to her home. She countered that she could pick

them up at my office. She had more reason to be in that part of town than I had to travel to hers. Time management is an important part of self care, she asserted.

As Cheryl and Mark reengaged in the rhythms of day to day life their connection with Children's Mental Health was ending. Whether or when it will be drawn on in the future is uncertain. Should the need arise, however, Cheryl knows what resources she can draw on and will not hesitate to do so.

#### Donna's story.

Donna spoke of her experience seeking help with her 16 year old son, Danny. Donna has been sole parent from the time of Donny's birth. The family lives in the inner city. Donna stated her preference to meet at my office rather than her home. I first spoke to Donna in response to a letter of referral from their family physician. Telephone contact was made through her instructor at a program to prepare single mothers on social allowance for entry to the work force. Ultimately Donna and her son elected not to connect with formal mental health services.

On calling to arrange a second meeting I learned that the family was preparing for an imminent move to another province. Donna thanked me for the opportunity to address her experience and expressed regret that her participation was ending.

Donna began her first conversation with me by very clearly addressing how the describing of a problem differed according to one's relationship to it. School staff focused mostly on his behaviour, specifically his absences from school. She related the differences to me:

I was basically told not to worry about why he wouldn't come to school, just make sure he got there. I said if we could understand why he doesn't want to come, he'd be there. Donny himself told me he had a mental block, which I thought showed a lot of insight for his age. He said I 'just can't get there, once I get there I'm fine.' ..You know it was a very confusing time.

At first Donna had assumed that the changes in Donny's behaviour were part of normal adolescent development. This assumption was supported by friends and school personnel. Additionally, she explained, her experience in her family of origin made her

reluctant to attach the stigma of a mental illness to him. She recollected:

My mom had pretty bad depression...I was raised that any type of mental illness is a bad thing. Evil type thing. If it does happen, you close the doors and you draw the curtains and you don't let on to anybody. You just function as best you can with what you have at that time..I think that stems from the way I grew up. You were just supposed to say mom was sick. So I think it's partly from my childhood, but I've got to take responsibility as an adult and a parent. I just thought this whole thing was Donny. Everybody kept telling me that's normal, teenagers act like that. I just saw it as a growing apart process. He wants his privacy, he wants to become his own person, and I didn't want to emotionally cripple him so I was giving him space. But I noticed it started going beyond that.

As Donna observed further changes in Donny she began to understand them as a cry for help. He had lost interest in working out and going out with friends in addition to his lack of motivation to attend school. Donny's sleep cycle was turned around. When she tried to speak to him he would say that he didn't care about anything. Donna's concern was mobilized on coming home one day to find Danny watching television with the volume turned off. She described looking at this person watching soundless TV and thinking that something was wrong. She went to her family physician who made a referral to Children's Mental Health.

While awaiting contact from Children's Mental Health, she approached the school psychologist. He told her that he would likely not see Donny until the following school year. Donna went to the principal who directed that Donny should be seen. She reported feeling that the school psychologist saw her as unassertive and enabling Donny's absenteeism.

Donna had approached the school many times on Donny's behalf over the years, even going to the school board. She was puzzled by his lack of success academically. She related her attempt to communicate this to the school administration.

He's been getting placed the last couple of years. He hasn't been getting promoted or passed. Grade eight he got placed. Grade nine he got placed, but I did say you can't pass him because he's not ready. Socially he's not ready...Actually he's displayed a lot of symptoms, I believe, of ADD... I went to (the school board office) and said you can't place him...speaking as a parent he's going to think he can get something for nothing, and put no effort into it, and he's going to get into the real world...and he's going to find out that if he doesn't do what's required he's not going to have a job and pay his mortgage. And I was told that he couldn't have ADD.

Donna began to question whether she was perpetuating the problem by maintaining

a focus on school issues. She wondered if she didn't want to understand or recognize the source of these problems. She described her effort to make sense of this situation.

I really racked my brains, and sat up a lot of nights and thought...Is it because he doesn't have a dog? Is it because he doesn't have a dad? Is it wanting so many material things and not being able to have them? But I couldn't see...how any one of these particular things were causing this. And then it hit me, this is beyond me. I've got to go get him some help because, and it was hard for me to admit, I'm not capable of dealing with this with him.

Until this point Donna had taken pride in her ability to do on her own, the best she could. She described raising Donny as a learning experience. At times, she added, she felt guilty, reflecting on what may have been overbearing or controlling behaviour on her part. She explained that her goal has always been to "teach him or show him to be independent ...as (he) gets older I try to guide him, but I really don't want to tell him what to do.

In some ways Donna felt her concerns would have been easier to deal with if Donny were younger. She would not have seen withdrawing as developmentally normal at a younger age. Her role in accessing service or attending appointments would be less tenuous. A number of appointments had been scheduled with Children's Mental Health. As she explained:

I think there was one appointment we had and I had the feeling I must have failed somewhere...and then it hit me I shouldn't do that...because I've tried not to be overhearing and controlling. But when he says I'm not going and he's six foot four and weighs around 250 pounds, what do we do here?...Eventually these are his decisions.

Looking back Donna, related a story illustrating her efforts to balance power and control in her parenting of Donny. He was six years old at the time.

It was Easter. We were colouring rabbits. 'Donny', I said, 'your rabbit is purple'. He said 'yeah'. I said 'well rabbits aren't purple'...and he broke his crayon and just sat there and I thought what's wrong with him. And then it hit me. He said 'yours is just a plain brown bunny, it isn't as nice as mine'. And I thought you know he's got a point. Why do all rabbits have to be brown. Why can't they be purple?"

Looking ahead Donna is curious as to what the future holds. She felt that she was engaged in a waiting process and a healing process. As she described waiting to see how Donny's experience with depression unfolds I asked what depression meant to her. Anna responded that she wasn't sure.

The only thing I had to base depression on was what I saw with my mom. It was pretty much a constant thing. I don't know where this (Donny's) depression is coming from, maybe it has a little bit to do with me, maybe it has everything to do with me, maybe it has nothing to do with me. I think in all fairness, I've been pretty good with Danny through the years. I tried to raise him so that he could cope and be on his own in the world.

As Donna spoke, I was struck by the prominence of stigma in her experience. At times in our conversation its presence seemed to cast a shadow across her sense of authority in relation to her own experience. I realized as well that the context of our relationship may have been having a similar effect, as she prefaced many statements with references to her lack of education. Consciously, I chose at times to ask questions or reflect on what had been said from my experience as a person diagnosed with and receiving medication for depression. This may have contributed to Donna's assertion that reviewing her story with me in a single follow up telephone conversation was sufficient. She felt comfortable with my sharing it with other participants and readers of this text. She thanked me for the opportunity to tell her story, commenting that it assisted her in "letting go of guilt feelings."

# Emily's story.

Emily separated from her partner Gordon when their son Jonathan was three years old. Gordon has been a graduate student for most of Jonathan's life. His availability to support Jonathan and Emily has, from Emily's perspective, been limited. Jonathan's visits to his father had been gradually decreasing from the original alternate weekends arrangement. Most recently Gordon has accepted an instructor position overseas.

Emily and Jonathan live in a suite in a house in an inner suburb. Emily ran a home based day care from the time of her separation until Jonathan entered junior high school. She is now a graduate student. Jonathan was thirteen and in grade eight at the time of our conversations.

Emily has chosen thus far to use others as sounding boards in her own describing of what a problem may be. There were three or four different points in Emily's life with Jonathan that she considered seeking help: when he was in grade two, grade five and grade seven. At one of these times a learning assessment was done at the school's request. He

received a year of speech therapy to assist with his language development. Emily consulted with friends who worked in helping fields such as child psychology and social work. She approached a formal children's service about the possibility of a group program. Ultimately the concerns she had were not sufficiently severe to overcome her mixed feelings about labeling and pursue formal help. She summarized her concerns about labelling as follows: "Would it be something that would get him the help that he needed or something that would negatively influence people's thinking about him?"

She wondered how the stresses associated with single parenting impact on children at life's natural transition phases. She questioned whether these parental stresses influence what kinds of supports a child may receive. Perhaps, she mused, these stresses may lead others to label the child with a learning disability or the family as dysfunctional. She has chosen to look at her son and his behaviour in a different way, recognizing the stress inherent in negotiating the world given his particular nature. Emily described to me her attempts to balance her awareness of her own and Jonathan's experiences as separate yet connected:

To some extent in reflection...I realize that these times (of help-seeking) were also quite frankly really difficult for me...In hindsight the kinds of things I saw...that caused me to think I wonder if he needs help were at least partly projections of my own need for help at that time...I don't just want to take over his process and say it was all me because I think regardless...stuff was going on that we both needed help with.... Right now I'm new kid on the block in a much larger school and I'm pretty much in the same position as my son was in grade seven and I'm doing some of the same things. I'm forgetting things, feeling overwhelmed and coming home at the end of the day without doing half the things I set out to do even though I'd written notes.

Through her experience Emily has come to question dominant stories in our culture about boyhood, about childhood, about institutionalized schooling. These questions underpin Emily's defining of a problem and loom particularly large for her now that she has started graduate school. School is a large part of both their worlds at the present. Emily discussed her belief that its influence is potentially destructive.

I'm recognizing...how strong you need to be to be inside this sort of place, that focuses so much on intellect and so much on Western methods of research and learning. And that does translate down to our kids and the institutions they're in...I don't really agree with having...that many kids in one place in the kind of way that we do and expect them to be there all day. Nor do I agree with a lot of the programming. It's very focused

on intellect and less focused on other parts of your being. It's very isolating. It isolates you from parts of yourself...and then it makes me wonder if a lot of kids get diagnosed with ADD when what's really going on is...a certain amount of depression that comes from the overwhelmedness of what their life is like.

Depression to Emily is not necessarily a bad thing. She voiced her recognition that it can be debillitating for some people. Her own mother suffered depression and struggled with thoughts of suicide at times. Emily shared her belief that from this experience she learned self reliance, an attitude that resonates in her personal understanding of depression.

I intuitively knew as a kid that she relied on me to be steadfast...so that certainly conditions how much I'm going to ask for help too... But for me (depression is) usually a primary signifier that something in my life is too overwhelming and I need to change it...It's not simply a matter of chemicals in my body...there's other components as well. And for me it's stress related. It's a way for some essential part of my spirit to shut down and regroup...and move on.

Living with depression, to Emily, involves finding some kind of mediation between a recognition of one's own nature and a recognition of the world around one. Part of this mediation involves choosing what parts of the world to engage with, choosing as she said "not to participate in aspects of the world around that are too crazy making: like refusing to read the newspaper for a couple of days or refusing to shop in certain places or participate in certain activities." She cited, as an example, that she and Jonathan have decided that too much structured activity detracts from their life, and have chosen to forgo the hectic scheduling within which some families conduct their lives. She believes that lot of her work as a parent is to make sure that her son son experiences a sense of balance in the development of his physical and spiritual being.

Developing a stronger sense of spiritual being is a lifeline for Emily. Feeling connected to something larger than herself, she believes, reduces her sense of isolation. She spoke of the connections in her experience with depression:

There are people who argue that we construct this reality to suit our needs. There people who say that it's real...I'm not prepared to get into those kinds of debates...it's a support for me...one I choose to follow or walk with...I've learned to work with it deep at the times I'm depressed, I see them not as, I don't see depression so much as an enemy or as something to be feared (but as) one of the many places that I come to in the journey of my life...that requires looking at because it's like a neon light saying something's going on. (Jonathan's) going to have his own journey with it and with his relationship with the world around him and inside him. So I don't want to project any of mine on him. But I do see us walking parallel paths. All I can do is share the benefits of mine with him and hopefully

there will be some connecting place that makes sense with him."

Emily explained that her understanding of depression includes a physiological component. She hopes to offer Jonathan an example and choices about maintaining his physical well being. Physical exercise although helpful, requires that they push each other a bit, as neither are naturally athletic. She cites healthy eating as another "kind of really obvious basic thing to deal with depression". Reserving the right to choose a weekly designated junk food day in her opinion, encourages choice, as well as respite on highly stressful days. Herbal preparations have helped Emily and she plans to offer this as a choice to Jonathan in the coming winter. Both Emily and Jonathan have, over the years, engaged with practitioners of alternative healing with a focus on energy systems. She found these approaches and the language used consistent with a spiritual way of being in the world.

The family has engaged in "mainstream counseling" at times to simply talk something through with someone who has some expertise with people's general experience. They maintain contact with their general practitioner. At the time of my first meeting with her Emily felt hesitant to approach additional formalized systems for Jonathan. She believed the benefits she gives Jonathan in terms of lifestyle are important and teach that there is personal power in trying things and building on small successes rather than directly seeking solutions with drugs or intense counseling. She explained it this way:

You've got to have something inside you that carries you through. You can't transfer all of your needs being met to these larger...systems directed by something other than your own agenda or values. I don't necessarily trust that the value system I have is going to be matched by the institution I'm working with...When I have (self reliance and connection to something larger) then I can pick and choose through the institutional kinds of resources.

Emily found that the values in the elementary school system were a better fit for her than in the junior high system. Her family of origin live in another part of the country. Their values and beliefs regarding boyhood and child development conflict with Emily's values and beliefs. Usually Emily simply accepts that they have differing world views. Holiday visits are a source of stress, however, she reported. Emily shared that she is more inclined to rely on the friendships she has developed over time, with people who know her and Jonathan and the journey of their lives. These people, she felt, would notice if something is

wrong and help her to make that connection.

Perhaps the difference between their experience and those of persons receiving a diagnosis of clinical depression, Emily reflected, is that so far they have only experienced a sense of isolation in small parcels of their lives and that this has influenced her help-seeking experience thus far. She summarized by saying:

I think there's a critical balance of isolation, where it's taking up pretty much all aspects of your life. I think that's a different thing, where suicide comes in...And I recognize that is where the line would cross for me with my son and asking for help.

### Weaving the Threads Together: Collaborative Analysis

Data analysis began immediately during the first meeting, even with the selection of participants. The narratives above reflect this beginning process. The following section arose out of a process of collaborative analysis between participants and the researcher. The result may be seen as a group story that underpins and joins the individual narratives.

Collaborative analysis began in earnest in January of 2001 as the researcher distributed a copy of each narrative to the four women (Anna, Brenda, Cheryl, and Emily) remaining. The fifth woman, Donna, agreed to have her story shared with the others and briefly reviewed it with the researcher in a telephone conversation.

In the process of engaging in analysis with participants, I became aware that my participation in the medicalized culture of therapy had restricted my perception of threads underlying their stories. The surface threads were easily discerned, quite likely because the context in which initial tellings occurred elicited illness and problem oriented narratives. It was only in physically and relationally moving from the role of outside observer that I was able to view the knowledge woven through these women's stories from a different perspective, at a different depth of field. This section attempts to trace the movement that occurred in this process of collaborative analysis.

#### From describing a problem to discerning a pattern.

Although participants identified a moment, a turning point, where the consideration

of seeking help arose, this was a point in the stream of time, of day to day life: parenting, schooling, family activities. Observations, wonderings and questions: is this just normal development, a healthy growing apart; that floated through consciousness now crystallized into a specific concern. An awareness that their child was disengaging not just from them, but also perhaps from life, pulled prior wonderings into a clearer focus. Understanding the seriousness of the mention of suicide most clearly, for the mothers, described a problem. This would seem self evident, yet one participant, Cheryl, was not informed of her son's expression of suicidal thinking until the third incident at school.

Cheryl's experience may serve to highlight participants' general experience that others may not share their description of a problem. In addressing her concerns about Jeremy, Anna encountered alternate interpretations within her family and at her son's school. Family members generally expressed their belief that Jeremy should simply grow up. Opinions amongst school personnel varied: he was immature, he had an attentional problem, his behaviour reflected anger turned inward. From school and her social network Donna received the mixed messages to back off, he was simply being a normal adolescent, and to take responsibility for getting him to school. Emily commented on systems' inclination to affix a label of a learning disability or attention deficit disorder without considering a child's social context. Brenda's experience illustrated that even once connected with the psychiatric system opinions as to the describing of a problem varied from practitioner to practitioner.

Even when the word depression was used, differing understandings of what this meant could confound efforts to coordinate solutions. Understanding depression as an illness meant, most often, recommendations for medication and therapy. Where depression was interpreted as anger turned inward, isolating the boy and his anger from others occurred. Views of depression as a character weakness resulted in encouraging the sufferer to "grow up". "Normal" adolescent depression required only that the parent ensure that the child fulfill their social obligation to attend school. Depression considered as a healthy response to demands of the outside world suggested managing the degree and intensity of contact with the world.

For many of the women these differing descriptions of the problem became a problem in their own right and led to questions about just where the problem was situated. Was it in fact within the child? Was it in the family? Was it in the school environment? Did the proposed solution or treatment become or create the problem?

The word description suggests an act of representing, a process of being represented (Pearsall & Trumble, 1996). "Time is the stars moving across the sky" Emily said to me at the end of our first conversation. Her statement suggests an unhurried contemplation of what is passing through one's vision. For the most part this was the experience of participants' description of the problem, occurring over time, looking back and reflecting.

Extending this process of describing and reflection into a process of collaborative analysis an alternate view of threads emerged. The outcome of a process of describing a problem varied according to one's relation to the experience. The point of view from which one views a fabric of knowledge influences the discerning of a pattern. This discerning of a pattern is what makes describing a problem (and implicit within that potential solutions) meaningful.

## From negotiating the system to nominating true supports.

The term negotiating the system suggests finding a way over or through a complex whole, a set of connected parts. Yet for most of these women the system was not experienced as connected. More than one mother spoke of connecting with the right person at the right time in the right place as a matter of luck. At some point in their journey participants experienced a sense that systems not only attempted to identify a boundary around a problem, for example distinguishing the illness from the child, but also to place a boundary between themselves and their child, perhaps even defining one of them as the problem.

For each of these women negotiating the system began with the education system.

Varying degrees of compromise or agreement were reached, even among personnel at the same school. Although individuals within the school system were helpful, participants' experience was that they could not count on having their concerns and attempts at solutions

heard as being legitimate. For the most part supportive individuals within the school system were able to offer moral support at best. Their power and ability to effect a solution based response was limited. Each of the participants acknowledged the differing agendas: for the system to promote the learning environment of the group, for themselves the well being of their child.

Anna's experience was that her concerns were not heard by Jeremy's classroom teacher and school principal. The school counsellor and social worker offered moral support, but their practical support was limited to making referrals to their family physician and to Children's mental Health. Ultimately Anna chose to transfer Jeremy to a school where she experienced a stronger sense of partnership. Brenda found the degree of support in working relationships with school staff to be a function of the individual relationships rather than a system wide value. Cheryl found that she needed to "keep on top" of managing relations with the school. Donna attempted to advocate for her son by meeting with school personnel, administration, and school division officials. Ultimately she learned that there was a limit to what support could be expected within the education system. Emily was clear that she did not expect to be working from the same values base. All in some way questioned the education system's exclusive focus on developing intellect and teaching content. It seemed that the culture's major socializing agent was teaching to send those who were different or needing special consideration elsewhere.

When speaking of depression as an illness one assumes that the health care system is the system to be negotiated. Only in Cheryl's story does this in fact clearly appear to be a system in the sense of a complex whole, a set of connected things or parts. Cheryl and Mark were previously connected to Children's Mental Health and a hospital based grief group by those providing care to her husband prior to his suicide. Cheryl's experience suggests that without prior explicit knowledge this system is such only to those working within it. To those initially encountering it, the mental health care system may be complex but the connections are not clear. Perhaps for it to be experienced as a system persons negotiating it require a sense of being at its centre.

Brenda entered into her experience with the assumption that there are people and

agencies who are there to help and all you have to do is call. Further on her journey she learned that the psychiatric community was failing her. After encountering varying descriptions of the problem within this system she began to educate herself, choose which descriptions she would consider, and, despite the very real challenges she faced, assert that it was selective help that she wanted. In particular Brenda shied away from the use of mobile crisis services. In her negotiation of the system she had been told more than once that Todd was the problem and might have to be removed to avoid destroying the family.

Anna, at the time of our first meeting, had made a brief initial contact with the mental health care system. Her experience included the necessity to introduce the education and health care systems to each other to clarify how resolution might occur. Contact with their family physician was experienced as practical, straightforward and supportive. He had assured her depression in children is common and medication can be helpful.

Emily also considered her family physician a resource, in terms of general health maintenance. Although she had friends who worked in social services and child psychology she chose to keep a healthy distance from the system with her concerns about Jonathan. Emily saw the system as "The system, prevailing political or social order, regarded as oppressive and intransigent" (Pearsall and Trumble, 1996). Her description of depression was not medicalized and she was reluctant to subject Jonathan to being labelled.

Donna's engagement with the formal health system was limited to their family physician. Her experience led her to be cautious about eliciting the stigma that accompanied a diagnosis with a mental illness. She also struggled with how much responsibility to assume for her 16 year old son, now considered legally able to consent to his own treatment.

Seeking help meant negotiating a description of a problem and its solution with informal as well as formal systems. Engaging with formal systems created a paradox. On the one hand, women experienced limited authority in describing a problem and solution. On the other hand, the lack of connection between components of the system left them with the responsibility of monitoring and managing the outcomes of these decisions. In collaboratively considering the process of negotiating the system it would seem that

ultimately participants nominated those resources that they experienced as sources of true support in their journeys.

## From stigma to significance.

For some of the women the burden of stigma outweighed the benefit of engaging with potential sources of help. Emily was reluctant to engage with formal systems as she was uncertain whether the potential benefits outweighed the repercussions of having her son labelled. Anna struggled with who to share Jeremy's diagnosis with, wondering whether the supports that might be gained would justify the anticipated judgment or criticism. Brenda observed how Todd's father and brother initially distanced themselves from his suffering by using dismissive labels like "nutcase" or "psychonut". Donna spoke most clearly of the effects of stigma related to her mother's chronic depression. Cheryl had encountered the effect of stigma in living with her husband's illness and resolved to resist its invitation to isolation.

External stigma was not necessarily related to a diagnosis of an illness, but also to other's interpretations of their child's behaviour. Brenda lamented that Todd's illness was not visible and this led others to misunderstand. Each of the women wondered whether they were responsible to some extent for their child's behaviour, or judged responsible by others. This internalized stigma was perhaps most isolating but unfortunately not unrealistic. Experience had taught these women to choose carefully who they approached for support lest they be burdened with yet another pronouncement of judgment. Perhaps in this sense a label "this child has an illness" would be less stigmatizing and isolating, a helpful clarification.

This clarification would be only partly helpful, however. Even with a diagnosis and reassurance from her friend and the family's physician Anna felt badly that Jeremy was medicated and wondered what she could have done differently. A diagnosis of depression linked their child to an ongoing story of depression in their lives. Donna initially was unable to comprehend that Danny may be linked to the story of depression in her family. Cheryl pondered whether she participated in emotionally disabling Mark.

Given the cited prevalence of depression persons approached for help are likely to have their own story of depression that visible or not will influence their responses. Stigma may be seen as functioning in these narratives as a response to, a judgment of, distancing from, or an attempt to impose a sense of certainty on an uncomfortable or unpredictable situation. The experience of identifying a distinguishing characteristic in itself was not necessarily a negative experience. As Brenda stated one source of frustration for her was the lack of a clear sign indicating the meaning or significance of Todd's behaviour. Re-viewing the phenomena of stigma as including signifying may be a more helpful approach.

#### From uncertainty to understanding.

Threads of uncertainty run throughout the stories of these mothers. Experiences with describing a problem, negotiating the system, and encountering stigma raised more questions than answers. Is my child sad, mad or bad? If he is depressed what does this mean? Am I talking to my child or the depression? Will he survive this? Will treatment help or hurt? Is this my fault?

The uncertainty associated with living with depression, even possible depression, in their children led participants to look for available explanations. Family stories of depression and dominant cultural stories about the role of mothers, particularly in relation to sons, offered limited resolution.

The same uncertainty that led to this search for available narratives opens space for the creation of one's own story, incorporating one's own experience and selecting threads from dominant narratives that offer support. Encountering persons who endorsed their emerging concerns was a major source of strength and support. Prior experience with or inside knowledge of the system increased understanding and with it mothers' sense of strength and being at the centre of their own experience. Each of the participants in their own way developed an understanding of what was within their power and what connections supported them outside of the limits of their own power.

#### Chapter Five

#### **Links With Other Narratives**

The first thread taken up in the construction of this text was that humans make sense of their existence through the use of narrative. The metaphor of weaving was chosen to illustrate how narratives or fabrics of knowledge may be constructed through the interlinking of themes or threads.

The review of literature on childhood depression, depression and families, and mothers and help seeking was presented as a fabric of knowledge that has thus far shaped research and practice. The process of crafting a particular fabric of mothers' knowledge of seeking help with a child suffering depression has been described.

Gadow (1996) described ethical narratives that influence nursing practice that I am choosing to extend to nursing research. A relational narrative, according to Gadow, is coconstructed to describe the good they are seeking. This coconstruction may overcome the silencing of the patient's narrative that occurs in paternalism and the silencing of the nurse's voice that occurs in paternalism.

Abma (1998), in a study using storytelling as a form of inquiry in a mental hospital, noted that "inherited" or "standard" stories sustained the practice of professionals and marginalized patients' experiences. When professionals were able to listen to patients' unheard stories the standard stories were enriched and facilitated changes in practice.

This section explores the links between the fabrics of knowledge described in the review of the literature and in participant's narratives. It is my hope that by so doing a relational narrative may be constructed that enriches the fabric of professional knowledge and facilitates changes in practice.

## Describing a problem, discerning a pattern

The description of youth suicide as a problem is a thread common to the fabric of research literature (Hollis, 1995; Fennig & Carlson, 1995; Adams & Adams, 1996; Modrein-McCarthy & Dalton, 1996) and participant narratives. In both these fabrics of knowledge suicide and depression are closely intertwined threads. The research literature

links youth depression and suicide to family discord, disturbed mother child relationships and poor communication in a noncircular way. That is, it is suggested that these factors within the family influenced the incidence of depression and suicide in youth.

Threads from participants' stories may enrich the complexity of this fabric of knowledge. Mothers described the pure fear they experienced when their child spoke of suicide, particularly when the family story linked suicide and depression. This fear led mothers to negotiate the system in search of help, despite the shadow of stigma and the conflicting,, at times mother blaming, problem descriptions they encountered. That is, help seeking engaged mothers in a larger system where they, at times, experienced discord, disturbed relationships and poor communication.

Poor communication with the larger system extended as far as the extreme of Cheryl's experience. She had come to understand depression as a potentially life threatening illness. She had advised Mark's school that he had lost his father to suicide, within the last year. Yet the school did not inform her of Mark's statements of suicidal thoughts until he told other children, until it essentially became public knowledge.

Could the fabric of knowledge reviewed in the literature contribute to a assumption that perhaps mothers could not be trusted to understand or act in the best interests of their children? This question is not intended to blame persons working within professional helping systems. Rather it suggests that perhaps the fabric of knowledge represented in the literature reviewed constitutes a narrative of paternalism (Gadow, 1996), in which mothers voices are silenced.

To pursue this question is to consider the effects of gender on mothers' help seeking experience. Until fairly recently where depression was accepted to be experienced by children it was presumed to affect girls more than boys (Hagerty, 1995; Modrcin-McCarthy & Dalton, 1996; Fasser & Dumas, 1998). I had anticipated that in this study I would be speaking to mothers about their experiences with their daughters. Yet all mothers who elected to participate were seeking help with their sons. The design of this study precludes any statistically significant explanations of this fact. It does raise some compelling questions. Were these mothers experiences of feeling unheard or disbelieved because they

sought help with boys? Did potential participants who sought help with daughters feel less need to have their experience heard? Were there assumptions among helpers approached that boys "act out", that they are unlikely to experience depression?

Threads in the literature reviewed explored the relationship between child and adolescent depression and family structure (Patten, Gillin, Farkas, Gilpin, Berry, & Pierce, 1997), family cohesion or support (Kashani, Allan, Dahlheimer, Rezvani, & Reid, 1995; Sheeber, Hops, Alpert, Davis, & Andrews, 1997), and family interaction patterns (Chiarello & Orvaschel, 1995; Dadds et al., 1992). On closer reading research and clinical narratives referring to "family" spoke of mother-child dyads. Mothers were described as critical (Chilcoat & Breslau, 1997; Pike & Plomin, 1996), too emotional (Dadds, Sanders, Morrison, & Rebgetz, 1992), unemotional (Oliver & Paull, 1995), unavailable (Rodriguez-Vega, Canas, Bayon, & Franco, 1996), too available (Gjerde, Block, & Block, 1991) and at best as lacking social support (Goodyer, Herbert, Tamplin, Secher, & Pearson, 1997).

Threads in the research literature represent a "snapshot" view of the relationships between depression in children and family. Participant narratives reflect, in part, mothers attempts to make sense out of these relationships over time within a larger systems context. A snapshot taken at any particular point within one of the mothers' stories could support any and all of the research findings, even those that would seem to be mutually exclusive observations. So that, for example, snapshots taken at any particular point in Brenda's story could support suggestions of mothers being too critical, too emotional, unemotional, unavailable, too available, or lacking social support. These suggested findings would arise out of observation of isolated incidents that fail to consider context and meaning.

Mothering and help seeking occur in a social context (Glenn, 1994; Pridham, 1997). Glenn's observation that "Motherhood ideology certainly encompasses multiple contradictions. Mothers are romanticized...and demonized..." (p.11) supports the threads linking the research literature and mothers' stories.

Jackson (2001) explored cultural message to mothers, particularly in their relationship to sons, that equate touch with dependence in a sense that weakens the self.

Jackson theorizes that a close physical bond between mothers and sons is essential and that

withdrawal on the mother's part. In her exploration Jackson described how the culture encourages the withdrawal of the mother in a number of ways. She asserted that "too much closeness is usually not the problem between mothers and sons- it is the anxieties around closeness, most of them culturally imposed, that can lead to damaging distance." (p. 68) In summarizing, Jackson offered that the self-censoring mother is only reflecting dominant ideas in our society about touch and intimacy, a Freudian influenced double bind that saddles women with guilt and ambivalence about their roles as mothers.

Jackson (2001) reflected that her own son did not automatically see their closeness and his autonomy as incompatible. She recalled how only when her son was ill did she feel unconstrained to simply be physically with him "in an animal way", simply being close to each other, connected to each other and temporarily disengaged from the outside world.

Maturana (1998) suggested that humans, like all mammals in their childhood, are dependent on love and can exist only to extent that adults behave in correspondence with their behaviour. The mother/child relationship is described as one of total trust and body acceptance, in which nearness and touch can conserve an expansion of love during the whole life span.

Maturana (1998) proposed that children move from a matriste to a patriarchal culture at the primary to secondary school transition and in so doing live the cultural injunction to grow up and become separate. A patriarchal culture was described as one in which both men and women exist in an environment that promotes competition rather than collaboration. Maturana suggested (1998) that this competitive psychic space evolved through a fear of scarcity and generates illness and conserves pain and suffering.

Maturana's (1998) description of patriarchal culture resonates with experiences related by participants. Mothers expressed concerns regarding the role of schools, in particular, in their son's lives and the lack of collaboration they experienced as they engaged in the process of seeking help. Could a weaving of these threads through the fabric of knowledge reviewed in the literature, contextualize and enrich understanding currently guiding practice?

### Negotiating the system, nominating true supports

Simmle and Nunes (2001) describe navigating or negotiating the system as the greatest frustration faced by consumers of mental health services. The system treats people as illnesses not individuals and fails to recognize their unique and distinct needs. This observation is offered not to discourage persons seeking help but to prepare for the task ahead. Simmle and Nunes provide an exhaustive list of resources available within formal and informal systems. Formal systems are listed as: family doctors, psychiatrists, psychologists and other therapists, mobile crisis units, assertive community treatment teams, and hospitals. Informal system resources include self help organizations, clubhouse and distress lines.

Mental health nurses are considered as "other therapists". Simmie and Nunes describe nurses as tending to work within hospitals and community agencies. They note that the work of mental health nurse in private practice is not supported through funding by provincial health plans. They make a similar observation in regard to psychologists. If public funds support the use of services provided by psychiatrists, hospitals and community agencies, how might this influence mothers' help seeking experience? Could the fragmentation of health care services experienced by mothers be economically driven?

Mothers seeking help for their children however also need to negotiate the education system. Although counsellors, social workers, and psychologists are resources within this system, their role is as a resource to school staff who work directly with students. As such their accessibility is even less clear to parents than that of resources within the health care system. Prior involvement with school based resources served as the primary source of knowledge for participants.

The World Health Organization has published a resource manual for teachers on the topic of suicide in children and youth (Bertolote, 2000). This manual is a source of information intended to assist school staff in managing suicidal students. What may be less helpful to parents, however, is that the presentation of this information indirectly suggests that the role of education staff is central. Family is referred to as either a risk or protective factor. School staff are advised how to make referrals to professional organizations with no

mention of communication or collaboration with family. For persons working within the primary socialization institution in our culture this may reinforce unspoken assumptions that parents are the problem or an obstruction to the work of this system.

Mothers' experience of formal helping systems reflected the existence of a service model of care (Hartrick, 1997). Helpers focused, structurally, on the pathology or problems in families. "A service model of care rests upon the assumption that (professionals) possess the knowledge and experience necessary to manage families' health and healing experiences." (p. 59). The expertise, technique and capacity of mothers to address these needs is pushed to the margins. Yet mothers' stories clearly describe their expertise and capacity.

Mothers' resulting sense of powerlessness, isolation and stigma may heighten the need to nominate true supports particularly within systems to which the well being of their child is entrusted. Sources of support identified in mothers' stories were persons who approached the help seeking encounter with an awareness of and respect for mothers' agency. Hartick (1997) proposes the develop models of practice that promote and enhance the discovery and enhancement of family capacity. How might nurses, whose practice spans the domains of individual, family, and community participate in a health promotion oriented model of care? How might the knowledge contained within these mothers stories and nursing's general narratives (theory) connect to influence the currently fragmented, service oriented models of care that may contribute to mothers' sense of stigma, isolation, and, at times, powerlessness?

## Stigma, significance

Kenny (2001) explored women's stories of the day to day impact of depression on their lives, specifically in relation to stigma. Internal stigma was described as self blame, remorse, feelings of being self indulgent or morally flawed. Family members, by virtue of association with another stigmatized individual, experienced associative stigma. Stigma was seen as arising within the context of a society that values images of work, independence, money, and prestige and serving as a barrier to diagnosis and effective treatment. Decreased

employment and housing opportunities, increased family stress and concerns about acceptance in the community were associated with the presence of stigma precipitating a downward spiral making recovery difficult.

A recent article in The National Post (Physician Visits, 2001) suggests that a 36 percent increase in physician visits for depression is evidence that stigma regarding depression has been overcome. The body of the text discussion focuses entirely on medical treatment of adults within the context of a patient physician relationship. This seems to suggest that medicalization is the antidote to stigma for adults who are able to identify their concern in the privacy of the consulting room.

Participants' narratives relate the experience of seeking help as bringing them into the public social domain. As such their actions and intentions are opened to public scrutiny. In the context of a service model of care this scrutiny seeks pathology. Stigma may be seen as an interpretive schema that exists within a service oriented model of care, it identifies and marks pathology from the perspective of an outside observer. This interpretive schema may serve as a dominant narrative which mothers may consider in their own attempts to signify or find meaning in their experience.

Mothers' stories contain interpretive schemas that may enrich the understanding of the meaning of seeking help with a child who may be depressed. A range of meanings of the term depression existed within participants' stories. The presence of depression may signify a need to change one's relationship to the outside world and events within it.

Depression may signify a body response to being overwhelmed by the stress of life events. It may signify a potentially life threatening illness. The story of depression within each participant's family influenced the meaning that this single word held for them. For some mothers' simultaneously contradictory meanings of this word heightened their sense of uncertainty.

#### Uncertainty, understanding

Uncertainty has always been part of human existence. Rituals, ceremonies, and divination (including theorizing) have evolved as practices to deal with uncertainty. Cohen

(1993) described the construction of an assumptive world view as protection against a full awareness of the human experience of uncertainty. Mishel (1990) discussed the sociocultural influences contributing to the value placed on predictability, control and mastery in North American health care.

Mishel (1988, 1990) described uncertainty as the inability to structure meaning or categorize an illness event. Mishel (1990) suggested that the process of living with the continual uncertainty of chronic illness would lead to a new world view in which uncertainty is accepted as part of a life of multiple possibilities. Mishel (1990) noted that some situations such as isolation or major care taking responsibilities could block or prolong this reevaluation of uncertainty and lead to behaviour resembling post traumatic stress disorder.

Selder (1989) described transition as both the genesis and resolution of uncertainty. The focus of the transition process structures experience in such a way as to find meaning in light of the person's expectations. Confronting the irrevocability (at least conditionally) of change is described as essential for engagement in the transition and in life. Returning to normal routines is said to provide a sense of reassurance, of being linked to reality and society.

Landis (1996), drew on Erickson's nursing theory as a conceptual guide in examining the relationship between uncertainty, spiritual well being and psychosocial adjustment in chronic illness. Findings suggested a strong positive relationship between existential well being and the reduction of distress. A possible interpretation offered by the researchers was that social support functions through the transcendent, spiritual common bond among people which allows them to share themselves with one another. This may lead to finding meaning in life, which in turn may be important in the process of self reorganization required for adjusting to chronic illness and assuming a new lifestyle.

Cohen (1993) in a grounded theory study explored how living with conditions of sustained uncertainty became part of the fabric of life for families. Parents of children with chronic life threatening illness experienced diagnosis as a rupture after which their previous reality no longer existed. Managing sustained uncertainty involved managing time, social interaction, information, the illness, and the environment.

The idea of managing suggests an ability to organize or maintain control (Pearsall and Trumble, 1996). Threads regarding uncertainty in mothers' stories were intertwined with a developing understanding of what was or was not within their power to manage.

Flaskas and Humphreys (1993) explore the ideas of Foucault with the aim of developing a recursive understanding of power in family therapy. They reflect on feminist writers identification of the difficulties of failing to acknowledge power while working in fields in which its effects are real and at times abusive.

Flaskas and Humphreys (1993) focus on what they understand to be the major features of Foucault's understanding of power. They conclude that power is always present and can be seen in everyday interactions, in the structure of relationships between people, in the creation of ways of thinking, forms of subjectivity and forms of knowledge. Flaskas and Humphreys further acknowledge the "subjugation of alternate and marginalized knowledges which comes about in the practices of power" (p. 42).

These ideas intertwine closely with threads in the stories of participants. The ways of thinking and structure of "helping" relationships was experienced by mothers as marginalizing their knowledge. I am consciously choosing to avoid the use of the word alternate with its suggestion of duality, that we consider either this knowledge or that knowledge as authoritative. Rather I am aiming to construct a relational understanding of these knowledges that might facilitate an understanding to underpin more collaborative practices.

# Chapter Six

### Loose Threads

"In order for nursing knowledge to be a credible base for development of both the discipline and health policy...the question we need to ask is whether our research has allowed for the creation of a tapestry or a sepia photograph." (DeMarco, Campbell, and Wuest, 1993). In this section I pose the further question what threads remain loose in this fabric? Where may other threads further enrich the fabric of knowledge created here?

Nursing and mothering involves work within the public and private domains, with attention to competing demands for attention at the individual, family, and societal levels. This work is not always acknowledged, visible or valued. This section seeks to explore how the knowledge guiding this work may be woven into a larger fabric guiding research and practice.

Grumet (1998) in examining the lived experience of women in their role as educators offers her belief that women must make space and time for themselves for their work to achieve clarity, community and insight. She suggests a search not only for evidence of the external forces that diminish; but also to recover one's own possibilities to remember, imagine and realize ways of knowing and being that can span the chasm separating private and public worlds. She cautions that silence certifies "the system" and maintains complicity with those who repudiate the intimacy of nurture in their own histories and work. These ideas, referring to the work of women educators and education researchers, are equally applicable to the work of nurse, nurse researchers and the underacknowledged, undervalued work of mothers.

Some awareness of the extent to which the culture of therapy reproduces the dominant culture can assist us in our search for a posture that is not wholly complicit with it (White, 1998). This posture can include a determination to: assist persons to explore the effects of dominant cultural narratives, privilege alternate frames of meaning, acknowledge one's location in the social world and its implications, and interview families about their experience of therapy. The experience of retelling is described as authenticating, bringing a sense of community into existence. Practitioners can further support this by acknowledging

the experience within the other's story in a way that respects their central position and reflects the change the practitioner has experienced as a result of this hearing.

Narrative ideas provide a natural link between research and practice. Moules and Streitberger (1997) discuss the contribution of narrative therapy ideas to family nursing, in particular their "focus on the deconstruction, or exploration, of the source of problem stories that constitute the life of a family and recruit family members into lives of suffering ....(and) that often marginalize family and individual stories of success and competency." (p. 366). Robinson's (1996) exploration of the process and outcomes of health care relationships pivotal to therapeutic change are equally applicable to nursing research. The nurse's relational stance of curious listener, compassionate stranger, nonjudgemental collaborator and mirror for family strengths is described as a significant intervention inviting healing (and understanding). Kenny (2001) suggests consideration of individual circumstances including the meaning of the illness. Acknowledging client's expertise and serving as an advocate within system are identified as means of reducing the experience of stigma. Expanding one's understanding of mental illness in society, including awareness that stigma also influences health care providers' views and actions is suggested.

Simmie and Nunes (2001), Kenny (2001) and others stress the importance of respectful listening, a simple but powerful action in a culture in which "we do not know how to not say anything." Many of the "nursing interventions" and "management strategies" proposed in clinical nursing literature reflect knowledge existing within the stories of participants in these studies. This could be interpreted to mean that nursing is "just an extension of mothering" (CBC TV: The National, 2001). Alternatively it may authenticate mothers' experience that their work is often not visible nor valued in the public world.

Where nursing work is acknowledged in discussions of negotiating the system it has been considered within a service model (Hartrick, 1997) of care that seeks pathology or problems that may be solved through the application of expert nursing knowledge. Hartrick recommends that nurses examine the worldviews and interests governing their practice and consider whether they are congruent with and support the principles of health promotion

that foster and enhance family capacity.

Keddy (1996) asserts that "because information is humanly constructed, nurses have the power to alter knowledge, and thereby bring about alternative ways of knowing and subsequent social and political change." (p. 381). Purkis (1997) states that "Research that seeks to strip away the context of practice because it introduces 'bias' or 'complexity' into the findings also seeks to remove the highly sophisticated knowledge of the 'social' used effectively by nurses and their clients. A perspective that seeks to surface concerns about 'social' factors influencing opportunities for taking up health-promoting messages cannot avoid the positioned and positioning effect of the health provider by suggesting that the client's situation is somehow separate from that of the practitioner."

It is my hope that this study extends a small thread to span the chasm separating private and public worlds. By linking threads from the fabrics of knowledge of research literature and mothers' help seeking experience, and examining the tensions that analysis of gender, interconnectedness, meaning and power suggest may maintain these links the beginnings of a relational narrative is suggested. Future research into experiences of and connections between those who care for children suffering depression may further understanding. In particular the experiences of women of colour, women of diverse cultural backgrounds, adoptive and foster mothers and fathers require further exploration.

#### **Epilogue**

As I engaged in this study I struggled with how much of my own voice to include in this work, which of my voices to include in this work. Ironically I found myself presenting this thesis to my examining committee while experiencing laryngitis. This presented a real opportunity to reflect on the use of my voice.

This study occurred over time and in the process I became aware of the multiple I's present in my experience of completing this work. I began as a student and neophyte researcher. I approached initial interviews with less than full confidence that I knew what I was doing. The pull to remain in the more comfortable role of health professional was strong. This may have influenced participant recruitment. It did not escape me that those electing to participate were, demographically, not unlike myself- early middle aged white women.

As the women participating and I attempted to balance competing demands on our time, scheduled meetings were at times missed, forgotten, remembered at the last moment. This, for me, opened up a sense of the common ground in our experiences in our multiple roles. I responded to this by including more of my selves in conversation...the mother I, the daughter I, the I diagnosed and treated for depression. Thoughtful inclusion of my selves in the research relationship enriched my understanding of what I was hearing.

This thesis is drawing for me now to a sense of completion. My practice continues. My lives and the lives of participants continues, the development of knowledge and understanding continues. I wish to close this thesis with a voice I heard throughout the crafting of this thesis, my daughter, Allaria, marching about the study/playroom in our home repeating a song from a Shari Lewis video:

This is the song that never ends
It just goes on and on my friends
Some people started singing it
Not knowing what it was
Now they'll continue singing it
Forever just because
This is the song that never ends....

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# Appendix A

# Invitation to Participate

Hi, my name is Fiona Odorico. I am a Registered Nurse and I work at The Community Services Program as a Children's Mental Health Clinician. I am currently working on my Masters of Nursing degree at the University of Calgary. My thesis is about the experience of mothers seeking help with children suffering with depression. I came to this question as I took time to think about my work as a mental health clinician and my experiences as a mother and member of a family affected by depression.

I am hoping to meet mothers who are willing and able to participate in conversations that will help me to understand your experiences. You are invited to participate in conversations with me at a location of your choice at your convenience. I anticipate that we will meet at least twice for approximately one hour each time. You are also invited to participate in group conversations with some of the mothers who have shared their experience with me. These conversations will occur at the Community Services Building at a mutually agreeable time. I anticipate we would meet at least twice for about ninety minutes.

If, as a mother, you have experienced seeking help with a child, from early childhood to late adolescence, who you were concerned was depressed I would be interested in speaking to you. It is not necessary for your child to have been diagnosed with depression by a health care professional. You may have sought help from persons other than health care professionals.

I am interested in speaking to a small number of women so that we may fully explore their experiences. I will return your phone call. If I already have enough volunteers I will thank you for your interest. If you are still actively seeking help for your child at the time of our conversation I may, as you wish, suggest, refer, or connect you with appropriate resources. Please call me if you would like to hear any more about the study or if you wish to participate.

Sincerely, Fiona Odorico (204) 958-9600

# Appendix B

# Consent Form

Research project title: Mothers' Experience Seeking Help with Children Suffering Depression

Researcher: Fiona Odorico

Research Supervisor: Dr. Beverly Anderson

You are being asked to participate in a research study. The purpose of this study is to learn about the experience of seeking help with a child suffering depression. It is anticipated that this study will assist nurses and other health professionals to better understand and will help mothers and children in situations similar to your own.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you a basic idea of what the research is about and what your participation will involve. Please take some time to read this form and to be sure that the information below is clear to you. If you would like more detail about something mentioned here, or information not included here, please ask.

If you agree to take part in this study, your participation will involve the following:

I will phone you to arrange a first meeting, at a mutually agreeable time and place. You will be asked to talk about your experience seeking help with your child. This conversation will be audiotaped. A second meeting will be scheduled at a mutually agreeable time and place. I will bring a written summary of your story and we will talk about what changes would be necessary for it to be a reasonable understanding of your experience. It is anticipated that each meeting will last about one hour. We may arrange to meet another time, if needed, to improve this understanding. You may, if you choose to, offer letters, journal entries, poetry, drawings or photographs that may express parts of your experience and assist in developing understanding. This is the first phase of this study and you may decide after these conversations that your contribution is complete at this point.

You will be asked if you wish to share your story with other mothers taking part in this study. If you consent there are two ways that you may contribute to the second phase

of this research. You may consent to sharing a written (with names changed) summary of your experience with a small group of women who will meet to talk about the experience of seeking help with their depressed child.

You may also consent to be part of group conversations with other mothers who will share stories of their experience. The purpose of these meetings is to improve understanding of mothers' knowledge of the experience of seeking help. The result of these group meetings will be a document or documents recording mothers' experience seeking help with a depressed child and their reflections on this experience. It is anticipated that the group will meet at least twice for approximately ninety minutes each time.

I will be keeping a journal as a record of my experience in the group. You will be asked if you wish to keep a brief journal, and/or have meetings videotaped, and/or simply engage in conversations.

These individual and group conversations are intended to gather and document your knowledge as a mother seeking help with a child with depression. These are voluntary, research conversations. You are the best judge of when to consider your participation complete or ended. In the unlikely event that your participation results in emotional distress that does not resolve in the course of our conversations, a referral will be made to a health care professional for counselling. I will remain available for support until a connection is made.

This study will be published as a thesis for submission to the University of Calgary. Parts of the thesis may be published in professional journals, or used for teaching purposes. In publications and presentations your identity will be protected through the use of a pseudonym. The location of the study will not be identified. Your name will be known only to myself, my supervisor, and the other women in the group. All tapes will be erased and written research records will be shredded three years after the study has been completed.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in this research project and agree to

participate. In no way does this waive your legal rights nor release the researchers, sponsors or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing service to your child and/or family.

Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have any further questions concerning matters related to this research, please contact:

Fiona Odorico, the researcher at (204) 958-9600

or

Dr. B. Anderson, Faculty Supervisor at (403) 220-7460

If you have any questions concerning your rights as a possible participant in this research, please contact the office of Dr. M. Reimer, Chair, Research and Scholarly Development Committee, Faculty of Nursing, University of Calgary, at (403) 220-4646.

Participant's Signature	Date
Investigator and/or Delegate's Signature	Date
Witness' Signature	Date

A copy of this consent form has been given to you to keep for your records and reference.